Deinstitutionalization and Community Inclusion of Individuals with Intellectual Disabilities in Ontario: A Case Analysis

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Submitted in partial fulfillment

of the requirements for the degree of

Masters of Arts

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St. Catharines, Ontario

Abstract

In the last few decades, there have been significant changes in the way people with intellectual disabilities (ID) live in many countries around the world. Large isolated institutions have been replaced by community-based housing. This study examined the deinstitutionalization process in Ontario and it's effects on the lives of three individuals with ID. A case analysis approach was used allowing for in depth evaluation of the quality of life of these participants following their discharge with a focus on family involvement, community engagement, and choice making. A discrepancy analysis between the Essential Elements Plan (EEP), constructed when they were entering the community placement, and the current living arrangements was also done. The results of this study suggested that with community living comes improvements in family interactions, community engagement, and decision-making. However, these improvements were found to be minimal. Also, little discrepancy was found between the EEPs and their actual placements.

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In the last few decades, deinstitutionalization and community-based living of individuals with intellectual disabilities (ID) have been widely accepted and adopted (Johnson & Traustadottir, 2006). Since the early 1980s the federal government in Canada has encouraged the depopulation of individuals with ID living in the institutions (Smith, 1981). In 1987 the Ontario provincial government announced that it planned to close its sixteen institutional facilities within twenty-five years (Lemay, 2009). The last three remaining institutions in Ontario were closed in 2009. With the closure of all the Ontario facilities, approximately seven thousand individuals have been relocated to community-based settings. The small residential units in the community typically housing up to five people have now replaced the institutional living model (Young & Ashman, 2004a). The deinstitutionalization policies and practices are based on the principles of community inclusion, choice making, and improving the quality of life of people with ID (Johnson & Traustadottir, 2006). Planning and implementation of these goals in the community-based residences have been the topic of much research.

Despite of all the closures of institutions in Canada, US, Australia and Europe, deinstitutionalization remains a controversial topic (Kim, Larson, & Lakin, 2001; Parish, 2005; Taylor, 2001). Numerous studies have examined the effects of relocation to community residences on the lives of people with ID (e.g., Conroy, Spreat, Yuskauskas, & Elks, 2003; Cullen et al., 1995; Dunt & Cummins, 1990). The literature on community living shows general improvements in the lives of people with ID following their discharge from institutions (Emerson & Hatton, 1996; Molony & Taplin, 1988; Young &

Ashman, 2004a; Lemay, 2009). However, advancements in community inclusion and social connections remain questionable (Johnson & Traustadottir, 2006). Some studies suggest early positive changes in their quality of lives that are followed by a leveling off or in some cases a decline (e.g. Cullen et al., 1995; Dagnan, Ruddick, & Jones, 1998). There is a need for continuous assessment of the quality and outcomes of services provided for individuals following their discharge and evaluation of the need for adjustments to planning and policy implementation should be made based on the results of these assessments.

The purpose of this study was to evaluate the Facility Initiative in Ontario and the impacts of deinstitutionalization on the lives of three individuals with ID. It examined the changes in the participants' quality of life (QOL), more specifically their involvement with family members, community integration, and decision-making following their relocation to the community. Furthermore, the transitional plans written for each individual before their discharge were examined and compared with their current placement. Inconsistencies between the plan and their community placements were identified and the reasons for these changes are discussed.

Literature Review

History of Deinstitutionalization

There is a long history of institutionalization of individuals with ID (Johnson & Traustadottir, 2006). The institutionalization of these individuals was proliferated by the eugenics movement. According to the eugenics ideas, people with disabilities were considered defective and their genes had to be eradicated. It was positioned that this was best achieved through institutional isolation (Trent, 1994). The first institutional facility

for people with ID in the United States was identified in the mid 1800s (Bruininks, Meyers, Sigford & Lakin (1981) and by 1860s institutions were growing in numbers (Scheerenberger, 1983).

In the last few decades, there has been a shift in ideology towards deinstitutionalization and community-based living of individuals with ID (Johnson & Traustadottir, 2006). The community-based residences are smaller living units compared to the large and isolated institutional living arrangements (Young & Ashman, 2004a). The deinstitutionalization movement inspired partly by the concept of "normalization" rejects the idea of eugenics and in turn promotes inclusivity, independence, and choice (Johnson & Traustadottir, 2006). The normalization principle emphasized the importance of providing individuals with ID the opportunity to live a "normal" life (Nirje, 1999). Though supported by many, the implementation of deinstitutionalization remains controversial (Kim, Larson, & Lakin, 2001). Parent advocacy groups, human rights movements, shifts in political philosophies and legal actions all played major roles in the depopulation movement (Landesman & Butterfield, 1987).

Ontario's first institution was opened in 1876 in Orillia and was later called the Huronia Regional Centre (Radford & Park, 1999). Originally designed to house less than two hundred people, it was later expanded to house close to twenty-eight hundred residents (Radford & Park, 1999). In 1951 Rideau Regional Centre was opened in Smiths Falls Ontario housing more than two thousand people. Concerns were raised about over crowding and poor living conditions at the facilities. Two years later parents of children with ID formed the Ontario Association for Retarded Children (OARC), now known as the Ontario Association for Community Living, out of concern for the lives of their

institutionalized children (Anglin & Braaten, 1978). They demanded and successfully obtained funding from the Provincial Government for school programs operated under the OARC.

According to Anglin and Braaten (1978) the deinstitutionalization movement in Ontario was fueled by a document written by Honourable Dr. Matthew Dymond in 1967 entitled *Services for Children with Mental and Emotional Disorders.* This document was inspired by an article written by a Toronto Star columnist named Pierre Berton. Berton visited Orillia in 1959 and later wrote an article describing his experience and poor living conditions at this centre (Anglin & Braaten, 1978). Dymond called for major changes and collaboration between different governmental departments with other professionals and volunteer groups (Anglin & Braaten, 1978).

In the 1970s following a report written by Walter B. Williston, recommending the closure of all institutional facilities in Ontario, the relocation of individuals with ID into the community was underway (Griffiths et al., 2009). In 1987 the Ontario government announced the plan to close all of its sixteen institutional facilities. In 2004 the pending closure of the last three remaining facilities in Ontario was announced. In 2009 the Huronia Regional Centre, Rideau Regional Centre, and Southwestern Regional Centre were closed and all the residents were moved into the community (Lemay, 2009).

Over the years, numerous studies have examined the impact of deinstitutionalization on the lives of people with ID and majority of these studies were conducted in United States, Europe, and Australia (Emerson & Hatton, 1996; Kim, Larson, & Lakin, 2001; Molony & Taplin, 1988). Overall, the literature on deinstitutionalization suggests that the lives of individuals with ID improve following

their transition into the community (Emerson & Hatton, 1996; Molony & Taplin, 1988; Young & Ashman, 2004a; Lemay, 2009). Deinstitutionalization and community-based living is now the standard of care for people with ID (Emerson, 2004).

Physical and Mental Health

Studies have investigated the physical and mental health of individuals with intellectual disabilities following deinstitutionalization. Some researchers have found lower mortality rates in the community residential settings (e.g. Hauber, Bruininks, Hill, Lakin, & White, 1982; Eyman, Borthwick-Duffy, Call, & White, 1988), however, in one study the mortality rates were found to be comparable to institutional levels (Strauss & Kastner, 1996). Certain factors have been found to be associated with higher mortality rates in this population. Hauber et al. (1982) found smaller residential settings to have the lowest mortality rates compared to larger institutional facilities. Individuals with ID are at increased risk of death from various causes compared to the general population (Tyrer & McGrother, 2009). In one study, the degree of intellectual disability was related to the mortality rate as individuals with more severe intellectual disability had a higher mortality rate (Eyman, Grossman, Chaney, & Call, 1990). Age is also an important variable affecting the residents' health following deinstitutionalization. One study found reduced symptoms and significantly improved psychiatric conditions after relocation for people less than fifty years of age and no change for those over the age of fifty (Wildrick, Braley, & Frawley, 1997). In general, older residents have been found to experience more health problems compared to younger residents (Heller, 1988).

Adaptive Behaviours

Many studies have examined changes in adaptive behaviours associated with relocation (e.g. Emerson & Hatton, 1996; Kim, Larson, & Lakin, 2001). The majority of these studies report an increase in adaptive functioning following deinstitutionalization (e.g. Conroy, Spreat, Yuskauskas, & Elks, 2003; Dunt & Cummins, 1990). However, a few studies have found no change in adaptive functioning after discharge (e.g. Nottestad, Stromgren, & Linaker, 2000) and in one study, Stancliffe *et al.* (2002) report a decrease in adaptive functioning compared to institutional living. In a review of the literature, Allen (1989) found variations in the outcomes of deinstitutionalization suggesting that not all the residents who have relocated from the big institutions have been found to improve in their adaptive functioning and sometimes the initial gains made were lost over time. A meta-analysis of the studies on adaptive behaviour gains following relocation of adults with ID found the most pronounced increases in adaptive functioning to be in the self-care domain (Lynch, Kellow, & Wilson, 1997). Few gains have been reported in the socialization and communication domains (Lynch, Kellow, & Wilson, 1997; Molony & Taplin, 1990). In one study, those individuals now living in the community with milder intellectual disabilities, shorter period of institutionalization, and larger increase in community participation displayed higher adaptive behaviour scores (Stancliffe, Hayden, Larson, & Larkin, 2002). A few studies reported a plateau effect in the gains in adaptive behaviour, which may be tied to both the educational opportunities available and the level of intellectual disability (e.g. Fine, Tangeman, & Woodard, 1990; Molony & Taplin, 1990).

Maladaptive Behaviours

Another area that has been the topic of much research is maladaptive behaviours displayed by people with ID following relocation with the majority of studies reporting no change in such challenging behaviours (Young & Ashman, 2004a). Some studies report that deinstitutionalization often but not always resulted in a decrease in maladaptive behaviours (Conroy, Spreat, Yuskauskas, & Elks, 2003; Emerson & Hatton, 1996). Still, a few studies report an increase in maladaptive behaviours following deinstitutionalization (e.g., Fine, Tangeman, & Woodard, 1990). Hill and Bruininks (1984) found that SIB was the most common type of problem behaviours followed by disruptive behaviours and aggression toward others. Predictors of maladaptive behaviours after deinstitutionalization included SIB, other behavioural problems, and the caretaker's ratings of participant's need for assistance (Nottestad & Linaker, 2002). In studies using direct observational methods reductions in challenging behaviour were observed. Studies using third party or proxy rating scales were more likely to find no change between pre and post-deinstitutionalization measures of maladaptive behaviours (Emerson & Hatton, 1996). The discrepancy between the findings of the studies using direct and indirect methods could be due to the frequency of maladaptive behaviours. The investigators observing the resident in a limited amount of time could miss the occurrence of low frequency behaviour. On the other hand, the staff could sometimes more accurately report the occurrence of these behaviours. Overall, findings in the literature suggest that maladaptive behaviours are not improving and in some cases even worsening following relocation (Young & Ashman, 2004a). These results are somewhat alarming and signal

the need for more research and implementation of behavioural strategies to reduce problem behaviours in the community residential settings.

Quality of Life

Measuring quality of life (QOL) of individuals with ID is challenging due to their communication deficits. Measures are limited because they rely heavily on feedback from third party informants rather than first person reporting (Felce & Perry, 1995). Bearing that in mind, studies show improvements in the QOL of people with ID living in the community residences (e.g. Cullen et al., 1995; Janssen, Vreeke, Resnick, & Stolk, 1999). Significant improvements are reported in the physical living conditions of the community residences compared to institutional living spaces (Cullen et al., 1995). In some cases though, these improvements in QOL are temporary and will level out after a couple of years. Findings of one study revealed a consistent development in QOL of an older population with ID over the first forty-one months after leaving the institutions with a leveling out after fifty-three months. The investigators of this study hypothesized that the leveling off in this case may be due to a ceiling effect (e.g. individuals reaching their desired activity level) or a combination of various factors such as greater exercise of personal choice, changing needs and preferences (Dagnan, Ruddick, & Jones, 1998). The results of a long-term follow-up study revealed increases in QOL for all community residences regardless of location, service provider, age, or level of intellectual disability (Young & Ashman, 2004b). In a different study, the type of residential living (e.g., smaller, more normalized housing environments) was related to QOL and activity gains while the degree of disability was not (O'Neill et al, 1990).

Family Contact

Negative views of deinstitutionalization held by family members before the relocation process have been reported in the literature (Larson & Lakin, 1991). Conroy and Latib (1982) found that families hold a more positive perspective on community living following relocation. They also reported that families who often demonstrated the greatest opposition to deinstitutionalization were those who experienced higher stress at the time of the initial institutional placement. Research found families to be concerned about high staff turnover in the community residential settings (Conroy & Latib, 1982). Family involvement has been associated with more positive attitudes towards the deinstitutionalization process for the family members than the absence of involvement (Heller, Bond, & Braddock, 1988).

Studies report an increase in frequency of opportunities and actual contact with family members following deinstitutionalization (Conroy, Spreat, Yuskauskas, & Elks, 2003; Cummins & Dunt, 1988). Conroy et al. (2003) examined the changes in quality of life of two hundred and fifty-four people with developmental disabilities following their relocation to the community using a pre–post design. Frequency of family contact was measured before and after deinstitutionalization. Results of this study suggest that before relocation approximately seventeen percent of the participants fell into the category of having no family involvement and after relocation only eight percent of these individuals had no family contact. Heller et al. (1988) sent two questionnaires to a sample of three hundred and thirty-five relatives of residents with developmental disabilities who were either recently transitioned from an institutional facility to smaller community units closer to their family members or were about to be transitioned. The second questionnaire

was sent one year after the first one. The questionnaire inquired about family reactions to the closure, medical status of the resident, family involvement with resident, family appraisal of the closure situation, and available social support resources for the resident. Time one data showed that the majority of relatives reported dissatisfaction with the decision to close institutions and they believed that the relocation and the change that goes along with it would have a negative impact on residents. At time two, however, attitudes towards the closure became significantly more positive. The family members reported greater satisfaction with the new residential settings over time and agreed that services in the community were an improvement over than those in the institutions. Heller et al. found one of the main predictors of family satisfaction with the deinstitutionalization process to be the degree of involvement with the resident.

Community Participation

Although many studies report improvements in community participation and community contact of people who have been deinstitutionalized, the evidence suggests that community engagement in this population continues to be very low compared to the general population or even to those individuals with ID who have lived in the community longer. Baker (2007) looked at the community participation of twenty-eight people with ID before and after relocation from institutions and compared these results to thirty-four individuals with ID who already lived in the community when their study began. All participants were assessed on a range of measures six months prior to the relocation of the first group of residents. Each participant in the resettlement group was reassessed six months after moving and each participant in the comparison group was reassessed in the eighteen-month period when the first and last group were moving out of the institutions.

The results indicate increases in the frequency and range of community use following relocation. However, community participation remained low compared to other people with ID living in the community. Furthermore, the findings of this study revealed that those individuals with higher adaptive scores were more engaged in their community. Another study shows an initial increase in participation in community leisure activities by the residents during their first three years with a leveling out after the fourth year of stay (Dagnan, Ruddick, & Jones, 1998). Data were collected five months prior to leaving the institutions and then at thirty months and fifty-three months after relocation. Questionnaires were completed based on interviews with staff and residents.

Two more studies on the effects of deinstitutionalization have found significant improvements in the opportunities for community integration and frequency of community contact following discharge (Conroy, Spreat, Yuskauskas, & Elks, 2003; Cummins & Dunt, 1988). In a four-year follow-up study, Cummins, Polzin, and Theobald (1990) compared the data from eighty-five participants with ID four months prior to relocation from the hospital to eight months and forty-nine months after discharge. Increases in community participation and community contact were maintained compared to the institutional levels but their frequency still remained low compared to the general population (Cummins, Polzin, & Theobald, 1990). Relocation to the community residential facilities has been shown to result in a more varied range of community leisure and social activities for the residents compared to their time in the institutions (Cummins & Dunt, 1990). Although some findings suggest that smaller-sized residences are associated with more opportunities for participation in community activities and contact with family and friends (e.g. Emerson & Hatton, 1996; Felce, Mair,

de Kock, & Saxby, 1985), the findings on the specific characteristics of the residential homes resulting in greater community integration remain inconclusive (Felce & Emerson, 2001). However, one study examining the quality of life of one hundred and fifty-four residents from forty-seven different community residential settings found resident adaptive ability and the amount of attention received from staff to be two key factors associated with community affiliation (Perry & Felce, 2005).

Decision Making

Several studies have also examined the changes in the frequency of choices offered to the residents following deinstitutionalization. Young and Ashman (2004b) investigated the frequency of choice making exercised by one hundred and four individuals with ID who were discharged from the institutions. Data were collected six months prior to discharge and at one, six, twelve, eighteen, and twenty-four months of community living. Choice making was found to increase significantly over time following relocation to the community (Young & Ashman, 2004b). Despite the increases in available choices for the residents, choice making is still very limited in comparison to the general population. In many cases the residents do not have a choice of with whom they live at the residence and the staff who work there (Johnson & Traustadottir, 2006). Stancliffe and Abery (1997) compared the levels of available choice for individuals with ID before and after relocation with those individuals who remained in the institutions. They found a significant increase in choice making favoring the individuals who were transitioned. However, the levels of choices offered to the residents living in the community remained low. In a longitudinal study, Dagnan, Ruddick, and Jones (1998) examined the QOL of twenty-nine older adults with ID living in the community after

leaving the institutional facilities. The assessments were done before the move and at three different times up to fifty-three months after the move. The results indicated initial improvements in the opportunities for choice making and then a decrease after forty-one months due to regularity of daily activities and staff familiarity (Dagnan, Ruddick, & Jones, 1998). Some studies show that individuals with higher IQ and higher levels of adaptive behaviours are more likely to exercise choice making (Perry & Felce, 2005; Stancliffe & Abery, 1997).

Increased opportunities for choice making have been associated with positive outcomes in adaptive behaviours (Heller, Miller, Hsieh, & Sterns, 2000), work performance, socialization, and communication (Kern et al., 1998; Lancioni, O'Reilly, & Emerson, 1996) for people with intellectual and developmental disabilities (Heller, Miller, & Factor, 1999; Kern et al., 1998; Lancioni et al., 1996). In a meta-analysis of the existing literature the impact of choice making on problem behaviour was examined (Shogren, Faggella-Luby, Bae, & Wehmeyer, 2004). The findings of this study reveal that choice-making interventions have clear benefits on quality of life and complexity of problem behaviours of individuals with intellectual and developmental disabilities.

Research suggests that within the community residential facilities, lower rates of problem behaviour have been reported when individuals are given the opportunity to make choices among different tasks and activities (Romaniuk and Miltenberger, 2001). In one study, Romaniuk et al. (2002) examined the effects of a choice-making intervention on problem behaviours maintained by social attention versus escape from demands. The results of this study showed that individuals who displayed escape-maintained problem behaviour had significant reductions in those behaviors when provided with opportunities

to choose among tasks. On the other hand, choice making did not have any effects on the problem behaviors maintained by attention (Romaniuk et al., 2002). In other words, if an individual displays problem behaviours to refrain from an unwanted task or situation, introducing choices can result in a reduction in that individual's problem behaviours.

Person-Centered Planning

Today, person-centered planning (PCP) is predominately used in the design and implementation of residential, recreational, vocational, and educational supports for people with ID (Robertson et al., 2007a). PCP was developed in the 1980s as a means to better understand and improve the lives of people with ID (Robertson et al., 2007). PCP entails principles and strategies aiming to enhance the experiences of individuals with ID by increasing community integration, promotion of choice making, increasing their engagement in preferred activities, and developing new skills (Holburn and Christine, 2007). PCP includes a number of approaches that focus on the individual's strengths and capabilities, and assess his or her needs in community settings. The planning should be a collaborative process that requires constant revisions to ensure the desired outcomes for the individual (Rudkin & Rowe, 1999). Once an assessment of the needs of the individual is done based on dialogue with the client, if possible, and other sources close to the client (i.e. family members, primary support staff, etc), the information is recorded within a lifestyle plan (Rudkin & Rowe, 1999).

Holburn et al. (2004) examined the impact of PCP for a group of nineteen individuals living in an institutional facility. The group who received PCP were compared with eighteen matched peers who received conventional Individual Service Planning (ISP). Their results indicated that eighteen people from the PCP group moved into a

community setting as compared to 5 people in the ISP group. Aside from hastening the transition process, PCP resulted in an improvement in the participant's QOL in the areas of autonomy, choice-making, daily activities, relationships and satisfaction. Robertson et al. (2007b) conducted a longitudinal study evaluating the outcomes of PCP in the UK. In this study, the efficacy and costs of introducing PCP were evaluated for ninety-three people with ID in four different locations in England over a period of two years. Introduction of PCP for those individuals who received a plan resulted in positive changes in social networks; contact with family; contact with friends; community-based activities; scheduled day activities; and choice. PCP was found to be efficacious, however, the results varied across participants and not all participants received a PCP within the timelines of the study (Robertson et al., 2007b).

In another study, Robertson et al. (2007a), examined the factors that are associated with the successful implementation of PCP. The results suggest that participants' level of functioning is not related to the outcomes of PCP, except that it increased contact with friends. On the other hand, individuals with mental health, emotional, medical, and behavioural issues, and those diagnosed with autism were less likely to receive a plan. Also, among those participants who received a plan, those with mental health, emotional or behavioural problems were less likely to benefit from it. The results also suggest that committed facilitators play a crucial role in the success of PCP. These findings must be addressed and changes in policies and practice need to be made to ensure maximum level of success associated with PCP for everyone. Barriers to successful implementation of PCP were identified including availability of trained

facilitators, availability of services, lack of time and reluctance of people other than paid support staff to engage in the PCP process (Robertson et al. 2007b).

Significance of Study

Despite the existence of an extensive body of literature on deinstitutionalization of people with ID, there is a need for more in-depth case analyses to depict the reality of life, both positive and negative experiences, in the community-based residences. The case study approach is essential for our understanding and humanization of the relocation process. Case studies are used to present facts and to contribute to our knowledge of an individual, group, or a particular situation (Yin, 2003). According to Naumes and Naumes (2006), "a case allows an in-depth look at a single organization, individual, or situation. Although this does not create 'significance' in a statistical sense, it provides the opportunity to study a single sample in great detail" (p. 33). Whereas survey research only relies on the memories of informants to describe a given situation, case-based studies allow the researchers to investigate and understand what happened in a particular sequence of events in great detail. The ability to study a situation in its actual setting is one of the advantages of case study research. On the other hand, one of the major disadvantages of case studies is the problem of generalization of results.

Assessing the QOL of individuals with ID is challenging due to their communication problems. In the majority of cases it is not possible to interview the individuals directly and therefore measures heavily rely on feedback from other sources close to the individual. Reliability of data can be improved by having multiple informants in the study. According to Naumes and Naumes (2006),

> Field research does require that the information gathered by the case writer be verified, in some form or another. One person within the organization making a statement involving judgment or values may not reflect the true situation within the entire organization. Where at all possible, information should be gathered from multiple sources. (pp. 53-54)

Improvements in the QOL of people following deinstitutionalization have been reported in the literature. More specifically there are significant improvements in their physical living conditions and participation in leisure activities. However, few improvements in social interactions have been reported (Lynch, Kellow, & Wilson, 1997) and when evaluating community contact, the majority of studies focus on family interactions alone. More research is needed to evaluate the extent of social connections in the community.

There are numerous studies on deinstitutionalization of people with ID in parts of the English-speaking world (i.e. UK, US, and Australia), yet limited research has been conducted on the Canadian depopulation projects (Lemay, 2009). With the closing of the last remaining institutions in Ontario, and transition of a large number of residents into the community, there is an urgent need for more research and evaluation of the deinstitutionalization process in Canada. It is expected that other institutional facilities across Canada will be closing in the near future, and more and more people with ID will be transferred into the community. Research on Canadian deinstitutionalization processes will potentially influence planning and policies made for the next generations of residents moving into the community.

The purpose of the current study was to evaluate the deinstitutionalization process of the current Facility Initiative in Ontario using a case analysis approach. This study used comprehensive data to provide a clear picture of the lives and experiences of three individuals with ID following their relocation process to the community. This study focused on community participation, community contact, and choice making exercised by people with intellectual disabilities living in the residential homes. Problems with the transitional planning, implementation, and support were identified and discussed.

The following specific research questions were examined:

1. What is the degree of family involvement of former facilities residents?
2. To what extent are there opportunities for participation in community leisure activities and interactions with community members?
3. To what extent are there opportunities for choice making?
4. What is the degree of discrepancy between the actual placement and the EEP? What are the types of supports needed to adapt to the plan?

Method

Participants

Three individuals with ID discharged from the institutional facilities across Ontario from 2006-2009 who are currently living in community residential settings have been selected to participate in this case analysis[1]. Recruitment letters where sent from the Ministry of Community and Social Services (MCSS) to the individuals, their residential agencies and/or family members. Those who consented to participate in the study were

[1] A team of researchers at Brock University under principal investigators Dr. Rosemary Condillac & Dr. Dorothy Griffiths has been commissioned to carry out a study examining the impact of deinstitutionalization on individuals with ID in Ontario. The Facilities Initiative Study is a multi-method study, and these data were collected as part of the Case Study portion of the study.

then assessed to meet the inclusion criteria. The participants were deemed incapable of giving independent consent therefore the consent of their substitute decision makers (SDMs) or agencies were required and assent was given by the participants directly. Participants were chosen based on age, gender, medical needs, psychological issues, and behavioural problems in order to include a sample representative of individuals with a variety of transitional challenges. Overall seven individuals form three different institutional facilities were selected to participate in the case studies from which three were randomly selected for the current analysis. Other researchers will be working with the remaining four participants to complete the case studies. Two of the participants came from the same facility and are currently residing in the same house, and the third participant was discharged from another facility and lives in a different house in a different geographic area.

Peter[2]**.** Peter is a forty-seven-year-old male diagnosed with developmental disability. He lived in institution A for forty years and was discharged in 2008. He was then relocated to a residential home and has been living there for the past two years. Peter's mother has passed away and his father now resides in a nursing home. He has two sisters also diagnosed with developmental disabilities. His cousin Frank is the only relative in contact with Peter and is his SDM. Peter's speech is limited mostly consisting of echolalia, however, he is able to communicate his wants and needs using single words. He is independent in the majority of his daily living routines. In general, Peter is in good health, however, he has been gaining a lot of weight over the years, which puts him at increased risk for developing high cholesterol, hypertension, and heart disease. Peter has

[2] All names are pseudonyms.

a history of behavioural problems such as self-injury, aggression, destructive behaviours, and elopement.

Angie. Angie is fifty-three years old and has a diagnosis of Rett Disorder. She is non-ambulatory and non-verbal but expresses herself through facial expressions. Angie was first admitted to institution A at the age of four. A few years later, she was relocated into a nursing home due to her medical needs. She was readmitted to institution A when she was sixteen years old and lived there for the next thirty-five years of her life. She was discharged only a few days before Peter in 2008 and now lives in the same house with Peter and four other housemates. Her parents are both deceased and her sister, Mary, is her SDM. Her medical diagnoses include epilepsy, hypothyroidism (insufficient production of thyroid hormone), spastic quadriplegia (inability to use limbs), and mild scoliosis (curvature of the spine). She is on a level one pureed diet with thickened juice or water due to her swallowing difficulties. She displays repetitive hand and foot movements associated with her diagnosis of Rett Disorder. She has no known psychological or behavioural issues.

Jane. Jane is sixty-four years old and diagnosed with developmental disability. She was eight when she first left her family home to live in an institution and was later moved to institution B where she lived for the next forty-five years. Jane had an older brother and a younger sister who passed away from pneumonia when she was two. Both her parents are now deceased and her brother and sister-in-law are her SDMs. Jane was discharged in 2006 and moved into her new home in the community where she lives with five other people. She communicates using simple phrases. Jane displays various

behavioural challenges such as self-injury, aggression, and disruptive behaviours. She does not have any psychological diagnoses or any medical concerns.

Measures

File review. The History Questionnaire (Griffiths, 2007f) was developed for this study to guide a comprehensive file review for each participant (see Appendix A). It includes sections on biomedical, psychological, sociocultural, and behavioural aspects of the individual's life prior to deinstitutionalization. The file review also focused on the Essential Elements Plan, an individualized care plan for each individual and the recommendations made for a successful transition into the community.

Standard measures. The InterRAI Intellectual Disability (InterRAI-ID; Martin, 2004) is a comprehensive assessment instrument designed to evaluate the needs of adults with intellectual disabilities living in different care settings. It includes three hundred and ninety-one items assessing individuals with ID across different life domains (i.e. cognition, communication, physical health, home environment, recreation, etc.). The InterRAI-ID is designed to screen for problems, identify strengths, and evaluate the quality of services provided for people with ID. Previous research has indicated the internal consistency and validity of the measures embedded in the InterRAI instrument among a population of adults with ID (Martin, Hirdes, Fries, & Smith, 2007).

The Quality of Life Instrument Package (The Brief Version) (Raphael, Brown, & Renwick, 1999) is an assessment package developed to measure the quality of life of people with developmental disabilities. It includes the Quality of Life Questionnaire and the Assessor Questionnaire. The brief version of the instrument is recommended for research since it reduces the full version assessment time by forty percent. The

psychometric properties of both full and brief versions of the instrument package have been measured in a large-scale study (Raphael, Brown, & Renwick, 1999). The findings of the Ontario-wide study demonstrate the reliability of the Quality of Life Instrument as well as its content validity, construct validity, and criterion validity (Raphael, Brown, & Renwick, 1999).

Semi-structured interviews. The Front Line Staff Interview (Griffiths, 2007e) was developed for this study as a semi-structured interview for primary staff to answer questions about different aspects of the participant's life after transition (see Appendix B). It includes sections on adaptation to the transition, setting and supports, daily routines, activities and community inclusion, changes since transition, and quality of life.

The Family Interview (Griffiths, 2007d) was developed for this study to fill in information on how the participant has adapted to the new living environment, staff, and other residents (see Appendix C). The family member is asked about the frequency of their visits, whether the supports provided for the individual are sufficient, and any challenges that have come up since the transition.

The Agency Administrative Staff Interview (Griffiths, 2007a) was used to ask the Executive Directors (EDs) of the community agencies about the type of supports provided to former facilities residents, adaptations made to the setting, and staff training provided for the transition to take place (see Appendix D). They are also asked how the agency's transitional plan compares with the Essential Elements Plan, and whether or not there are discrepancies and why.

The Facility Planners Interview (Griffiths, 2007c) was developed for this study to be used with Regional Facility Planners, who were contracted from the MCSS to plan the

participants' transition into the community, to comment on the type of supports arranged, adaptations made to the setting, and how the plan was individualized (see Appendix E). They were also asked whether the Essential Elements Plan captured the needs of the person and how it compared with the transitional plan.

Observations. An observation sheet (Griffiths, 2007g) was used to record the participant's activities during the first ten minutes of every hour over eight-hour days representing a typical day in the life of each participant (see Appendix F). Two research assistants collected the data at the same time for reliability.

Discrepancy Analysis. Discrepancy Analysis (Griffiths, 2007b) was developed to measure the discrepancy between the EEP and the community placement (see Appendix G). The EEPs are transitional plans written by the facility planners prior to each individual's discharge. They include historical accounts of the individual, recommendations for future community placement and types of supports needed. Based on observations and interviews, information was gathered about the type of setting including the layout of the house and the participants' bedrooms, the staffing ratios, access to professional services, and leisure activities and was later compared to the recommendations made in the Essential Elements Plan.

Training

The two research assistants (RA) collecting the data for this study were graduate students in Applied Disability Studies at Brock University. Prior to commencement of the study, they each were required to complete a three-day training on the implementation of the measures and the procedure of the study.

Procedure

1. Participants were recruited and consents were obtained form the SDMs.
2. At the beginning of each visit, assents were obtained from the participants directly. They were asked if it was all right for the research assistants to be there and collect information about them.
3. Visits were scheduled with the agencies and information packages including the consent forms for staff, family members, EDs, and facility planners (see Appendices H-K) were mailed out prior to the visits.
4. A comprehensive file review on each individual was conducted prior to the visits. Once consents were obtained, the individuals' institutional files were moved to the Hephurn Block at the MCSS. All the institutional records (i.e. medical, behavioural, psychological, sociocultural, etc.) were closely examined and data from the files were transcribed onto the History Questionnaire (Griffiths, 2007f).
5. During the visits, the standardized measures including the InterRAI-ID (Martin, 2004) and Quality of Life Instrument Package (The Brief Version) (Raphael, Brown, & Renwick, 1999) were completed with the help of the participant's primary support staff.
6. Four semi-structured interviews with front line staff, agency Executive Directors, Regional Facility Planners, and family members were completed. Field notes were taken independently during the interviews by two research assistants and were later compared for consistency.
7. Direct observations of interactions throughout the daily life of the individual were also done.

8. Behavioural and medical records including incident reports for the previous months of stay in the agency were reviewed.
9. A discrepancy analysis between the EEP and the actual placement was done. Any changes to the plan and reasons for those changes were recorded based on interviews with agency staff, regional planners, and family members. Data were examined closely for shared experiences and similarities across different participants.

Analysis

Data from pre and post transition were examined for each participant (i.e., changes in family interactions, community involvement, and choice making) and were compared across the participants for similarities or discrepancies in the findings. In addition, the implementation of the EEPs were analyzed and any changes made to the plans and reasons for these changes were identified based upon interviews with the agency staff, regional facility planners and families. Cases were first examined individually and subsequently a trend analysis was done across the cases to identify repeated experiences.

Results

The data reported in this section provide descriptions of life experiences of Peter, Angie, and Jane before and after their discharge from the institutional facilities.

Degree of Family Involvement

Peter's pre data for family involvement. Peter and his cousin Frank have a strong and supportive relationship (InterRAI-ID, p. 2; see Table 1). Prior to Peter's discharge, Frank visited him on average a couple of times a year at the institution

(Essential Elements Plan, p. 3; File review). Although Frank took Peter to visit his mother before she passed away, Peter has not gone on a visit to Frank's house and has not been on any overnight visits at his family's house (Family Interview; InterRAI-ID, p. 2). Frank was involved in Peter's planning process and met with the facility planner on several occasions. He also visited the new house before and immediately after the transition to ensure Peter's needs were being met (Facility Planners Interview; Essential Elements Plan, p. 3).

Peter's post data for family involvement. Since Peter moved into his new house, his relationship with Frank has remained strong (InterRAI-ID, p. 2). Frank visits him on average every three to four months (Family Interview) and he communicates with the agency regularly and support staff will keep him informed about Peter's well being (Family interview; Staff Interview). According to Frank, "whenever there is an event with Peter, they call to let me know what's going on. If he has an issue they let me know" (Family Interview, p. 2).

The distance from Frank's house to Peter's new house is about a ten-minute drive farther than it was to the institution. When Frank comes to visit Peter, they occasionally share meals together (Staff Interview). Frank states that he wishes to visit Peter more often in the near future:

> I haven't visited much with my personal issues. Probably less than half a dozen times since the move. I hope to do more in the summer. Both my parents are ailing, so that took all my time. Calling is not worth it to be honest. I have taken him to see his mom not from here but from institution A and when he saw

> her, he just melted and had tears on his face. We've also visited his dad since the move to this residential setting. (Family Interview, pp. 2)

So far, Peter has not gone on a day or overnight visit to his cousin's home (Staff Interview; Family Interview; InterRAI-ID, p. 2). Peter has also received a visit from one of his sisters who lives in another residential setting close by (Agency Administrative Staff).

According to the ratings on the Quality of Life Questionnaire, there are some opportunities for Peter to spend more time with his family and he is very happy with his closeness to his family, however Peter does not make decisions about spending time with his family (see Table 2). The facility planner stated:

> The family (a cousin) was involved with this person. The cousin met with me and came to the home several times to visit and to ensure this person's needs were being met. He voiced his concerns about his cousin's safety and his concerns were addressed. Typically once the move has occurred the facilitator's role is finished. I didn't have any further contact with the home, as my contract came to an end. Another planner followed up with this home for the 3 months follow up. In fact most of the placement, which occurred towards the end of the initiative was not followed up by me. I did the planning and identified the placement, but didn't necessarily follow it through. Nature of contract work. (Facility Planners Interview, pp. 2).

Overall the frequency of family visits and degree of family involvement has not changed for Peter from before to after deinstitutionalization (see Table 1).

Angie's pre data for family involvement. Angie and her sister Mary have a strong and supportive relationship (InterRAI-ID, p. 2), Mary rarely visited her sister while she was living at the institution (Essential Elements Plan, p. 3). Angie did not leave the institution to go on any day or overnight visits to her family's house (InterRAI-ID, p. 2; see Table 1). Mary took part in the planning process for Angie's transition (Facility Planners Interview). She visited the home before Angie moved in and was quite pleased with the new setting (Facility Planners Interview; Family Interview).

Angie's post data for family involvement. Since Angie's relocation, there has been a slight increase in the frequency of Mary's visits although they are still infrequent (Staff Interview; Family Interview). When asked about the frequency of her visits with Angie, Mary responded, "not all that often. It's not consistent. It varies. She has not visited us" (Family Interview, p. 3). According to Angie's support staff, "it appears that Angie's sister Mary has visited her more often here in the home than previously, however visits are infrequent" (p. 7). Mary lives about an hour away from Angie, which is about the same distance to the institution where she lived previously (Facility Planner Interview; Family Interview).

According to the ratings of the InterRAI-ID, the two sisters continue to have a strong and supportive relationship (see Table 1). Mary has regular phone conversations with staff to stay informed about her sister's well being, however Angie is unable to communicate over the phone. "There is good communication. They call whenever anything comes up. I'm never ever worried that she isn't well taken care of" (Family Interview, p. 3). To date, Angie has not visited her sister's house (Family Interview; Staff

Interview). One of Angie's cousins has also visited her at her new residence, which according to the Staff Interview did not occur when she was living at the institution (Staff Interview). The Facility Planner pointed out that:

> Angie has a sister who was involved in the planning. The sister also came to view the home and has continued to visit the home post discharge. She was very pleased with her sister's new home in the community, and is made to feel welcome. (Facility Planners Interview, pp. 2)

The scores on the Quality of Life Questionnaire suggest that Angie is somewhat happy with how close she is with her sister and she has a lot of opportunities to spend time with her family although she does not make decisions about these visits (see Table 2). According to Angie's pre and post data, the frequency of family contact has slightly increased after relocation.

Jane's pre data for family involvement. Tom and Donna (her brother and sister-in-law) lived in a different city when Jane was living at the institutional facility and did not visit her often (Essential Elements Plan, p. 4; InterRAI-ID). Jane did not communicate with her family on the phone, and she also did not go on any day or overnight visits to his family's house (InterRAI-ID, p. 2). According to the InterRAI-ID scores, Tom and Donna did not have a strong relationship with Jane prior to her relocation (see Table 1). However, based on the Facility Planners Interview it is evident that they had a lot of input into Jane's transitional planning. The planner had a meeting with them and their needs were discussed. Drafts of the Essential Elements Plan were sent to them for their input. They were familiar with the potential agencies and were adamant about not wanting certain agencies for Jane. During the times they were not in

town to attend meetings, they participated through teleconferencing (Facility Planner Interview).

Jane's post data for family involvement. Since Jane moved into her new place of residence, her brother and sister-in-law receive weekly updates from staff on how Jane is doing and correspond with the agency's Executive Director regularly to communicate their likes and dislikes regarding her living arrangements (Agency Administrative Staff Interview). Tom and Donna have a strong and supportive relationship with Jane (InterRAI-ID, p. 2; see Table 1). They give all consents regarding medication changes or any other medical, psychological, or behavioural issues that come up with Jane (Agency Administrative Staff Interview). Jane lives a lot closer to them now and she is able to visit them regularly in the summertime when they stay in town (Staff Interview; Family Interview). According to Tom,

> We could go every day if we chose to. It's about a half-hour drive. Jane is non-verbal so calling her is not an option, but we can easily call staff. We have had Jane visit our home several times and this is easily arranged. (Family Interview, pp. 3)

Jane has visited Tom and Donna at their house and shared meals with them but she has not stayed overnight (InterRAI-ID, p. 2; Staff Interview; Family Interview). Due to Jane's communication deficits, Tom and Donna are not able to speak to her on the phone (Family Interview; InterRAI-ID, p. 2).

Spending time with her family is very important to Jane, however according to the staff ratings on the Quality of Life Questionnaire, she is not completely happy with the degree of closeness she has with her family (see Table 2). Jane has a lot of opportunities

to be with her family, however she does not make decisions about spending more time with her brother and sister-in-law (Quality of Life Questionnaire, p. 3). The degree of family involvement and frequency of contact has changed for Jane with relocation to the community (Staff Interview). According to the support staff, Jane's brother and sister-in-law "contribute to the personal plan, give advice about medical concerns, contribute emotional support in the form of visits, and inform themselves about any other concerns" (Staff Interview, p. 6). When asked about the family's involvement in Jane's transition, the ED responded that they are,

> Very involved. The family dictates the pace of their involvement. A lot of input in agency meetings, input into transition, lots of email contact, involved in the personal lifestyle plan, they give all consent (e.g., med changes), weekly updates, agency offers family their level of involvement. The family communicates with ED regularly to communicate likes and dislikes. (Agency Administrative staff Interview, pp. 2)

The facility planner was asked about the family's involvement in the transitioning process:

> I had a meeting with Jane's brother and sister-in-law at their house and reviewed the family needs. When they were out of town they participated in the meetings via teleconferencing. I sent them drafts of the Essential Elements Plan and they had their input. They were asked where they wanted her to move. We spoke a couple of days after the transfer to ensure things were going well. After that there was a 3-month follow up meeting that the family attended to discuss the transition. (Facility Planners Interview, pp. 2)

Overall the data show an increase in the frequency of family visits and degree of involvement after Jane was transferred to the community residential setting.

Opportunities for Community Engagement

Peter's pre data for community engagement. When Peter was living in the institution, the majority of his outings were done around the center (Essential Elements Plan, p. 4). These included walks, tractor rides, and social events such as dances and concerts with close supervision (Essential Elements Plan, p. 4; InterRAI-ID, p. 2; File review). Peter enjoyed going on bus rides and went on occasional trips to camp. However, camp has not been a success for him due to his elopement and constant running to the kitchen area creating a lot of stress for staff and for Peter himself (Essential Elements Plan, p. 4). He is relatively at ease interacting with others and doing planned activities however, he does not pursue involvement in such activities at the residential setting or in the community (InterRAI-ID, p. 2). According to the scores on the InterRAI-ID, Peter does not participate in social activities of long-standing interest (see Table 3). When asked if he preferred change in frequency, variety, or level of participation in leisure activities, Peter could not respond (InterRAI-ID, p. 2). In general, the frequency and variety of community outings were quite low when living at the institution and interactions with other community members were infrequent.

Peter's post data for community engagement. Following deinstitutionalization, there are a lot of opportunities for Peter to go on different outings in his community (Quality of Life Questionnaire, p. 4; see Table 2). Peter regularly dines at restaurants, goes to the movies, goes shopping, and goes for walks. He plays bowling, basketball, and in the summertime he plays baseball (Staff Interview; Assessor Questionnaire, p. 2). He

also volunteers at a local food bank (Staff Interview; InterRAI-ID, p. 2, Assessor Questionnaire, p. 7). He is at ease interacting with other people. He is also at ease participating in structured activities and pursues involvement in those activities at his residence and in the community (InterRAI-ID, p. 2). He also is frequently involved in social activities of long-standing interest. Peter was asked if he preferred any changes to his current recreational activities but he could not respond (InterRAI-ID, p. 2). The staff ratings on the Quality of Life Questionnaire suggests that going on community outings is very important to Peter and he is pleased with the frequency and variety of his community outings (p. 4). There are a lot of opportunities for him to go on different outings in his community and he makes his own decisions about where he wants to go (Quality of Life Questionnaire, p. 4). He is also quite happy with his socializing and visiting others in the community and there are some opportunities for him to have more social interactions if he chooses to (Quality of Life Questionnaire, p. 5; Assessor Questionnaire). He does not approach others while on outings, but when they do approach him Peter seems to enjoy their company (Staff Interview; Assessor Interview, p. 6). When the research assistants were at his house conducting the interviews, Peter made a lot of eye contact and frequently smiled at them (observation Sheet). Peter is accepted by his neighborhood and interactions with his neighbors and other community members have been positive. "Once Peter eloped and ended up across the street in a convenience store. The owner sat him down, gave him a drink and called the house" (Assessor Questionnaire, p. 6). According to the staff, one of the drawbacks of country living is that the opportunities to make strong community connections are limited (Staff Interview). The residents often do not come into contact with other community members unless staff

drive them to get to desired locations (Staff Interview; Observation). Peter has some access to community-based education and employment opportunities. He also has full access to social and medical services as well as community buildings (i.e., shopping malls, libraries, restaurants, recreational facilities, etc) (Assessor Questionnaire; see Table 5).

Angie's pre data for community engagement. While living at the institution, Angie attended church, and special occasion parties at the facility. She spent time at the activity center and went on walks inside the institution. She occasionally went on bus rides outside the institution and in the summertime went on trips to the lake (Essential Elements Plan, p. 4; File review; InterRAI-ID, p. 2). She was at ease interacting with others and doing planned activities but she did not pursue participation in such activities (InterRAI-ID, p. 2). She was not involved in any social activities of long-standing interest. Angie was not able to communicate if she preferred any changes in her recreational activities (InterRAI-ID, p. 2; see Table 3). Angie did not go on frequent outings outside the facility and in turn did not come in contact with other community members often.

Angie's post data for community engagement. At her new residence, Angie has a lot of opportunities to go on community outings and she seems content with the frequency and variety of these outings (Quality of Life Questionnaire, p. 4). Angie goes to church, movies, shopping, library, community parks and beaches regularly (InterRAI-ID, p. 2; Staff Interview). It is very important for Angie to go on different outings in the community and she makes decisions about where she wants to go (Quality of Life Questionnaire, p. 4). The rating on the Quality of Life Questionnaire suggests that she is

very happy with the frequency and variety of her community outings (see Table 2). She is also comfortable doing planned activities and often pursues involvement in those activities (InterRAI-ID, p. 2). There are many opportunities for her to spend time with and socialize with other community members and she is at ease interacting with them although she does not make decisions about her social life (Quality of Life Questionnaire, p. 5; InterRAI-ID, p. 2). She regularly participates in social activities of long-standing interest (InterRAI-ID, p. 2; see Table 1). She is a Red Hat Society and Primetime Fellowship Member where she comes into contact with various members of her community (Staff Interview; Assessor Questionnaire, p. 6).

According to the Staff Interview, "people from organizations we have joined are always happy to see her and include her in the activities. Contacts have been positive (p. 7). Her immediate neighborhood accepts and welcomes Angie (Assessor Questionnaire, p. 6; see Table 5). Angie does not have access to educational or employment services. She does however, have full access to community-based social and medical services. She also has access to community-based buildings (Assessor Questionnaire, p.7). The country setting however, restricts Angie's community integration to some degree. Access to community leisure and social activities are somewhat limited compared to the city and less convenient as staff often need to drive long distances to get Angie to a park or other locations in the community (Staff Interview; Observation Sheet).

Jane's pre data for community engagement. Back in institution B, Jane went swimming, attended concerts, and went on walks around the facility (InterRAI-ID, p. 2; see Table 3). She initially attended church but because of her disruptive behaviours had to stop attending church both in the community and at the center (Essential Elements Plan,

p.7; File review). She was at ease interacting with others and participated in structured activities but did not pursue involvement in those activities. She did take part in social activities of long-standing interest (InterRAI-ID, p. 2). When Jane was at the institution, the frequency of her community outings outside the facility and community interactions was quite low.

Jane's post data for community engagement. Since her move, Jane has many more opportunities to visit different places in her community and she makes decisions about the type of outings she wants to go on (Quality of Life Questionnaire, p. 4; see Table 2). She frequently dines at restaurants, attends church, goes shopping, and goes for walks. She also goes swimming at a local community center. In the summertime, she goes to local attractions such as museums, parks, and farms (Staff Interview; InterRAI-ID, p. 2). Jane is pleased with the number of places in the community she gets to visit (Quality of Life Questionnaire, p. 4). When asked if she wanted a change in her recreational activities, she could not respond (InterRAI-ID, p. 2).

Jane is at ease interacting with others and participating in structured activities. She does not pursue involvement in activities in her residential setting or in the community (InterRAI-ID, p. 2). According to the scores on the Quality of Life Questionnaire, there are a lot of opportunities for her to interact with other community members (p. 5). She participates in social activities with others (InterRAI-ID, p. 2), however she is not happy with the degree of her social interactions (Quality of Life Questionnaire). Interactions with others when she goes shopping and to restaurants are generally positive (Staff Interview; InterRAI-ID, p. 2). When she goes out shopping or is dining at restaurants, people smile at her and speak to her in a polite manner (Staff Interview). Overall she is

accepted by her immediate neighborhood and community members, although her neighbors have complained about her screaming a few times (Assessor Questionnaire, p. 6). She has access to community-based social and medical services as well as any community-based buildings. Currently she does not have access to any educational or employment services (Assessor Questionnaire, p. 7; see Table 5).

Opportunities for Choice Making

Peter's pre data for choice making. According to the scores on the InterRAI-ID, Peter's ability to make decisions was severely impaired and he rarely made any decisions when living at the institution (InterRAI-ID, p. 2; see Table 4). At the institution, staff woke up Peter at a certain time everyday (Essential Elements Plan, p. 5). He had limited choice when it came to the food he ate. He could choose his outings but there was not always enough staffing to take him out (File review; Essential Elements Plan, p. 5-6). Due to Peter's limited verbal skills, he could not respond when he was asked if he preferred changes in his living arrangements, daily routines, recreational activities, or employment (InterRAI-ID, p. 2). Although it is difficult to assess the extent of his choice making opportunities based on file reviews and the scores on the InterRAI-ID alone, the data suggest that Peter did not have a lot of opportunities to make choices in his day-to-day life.

Peter's post data for choice making. Based on the scores on the post InterRAI-ID, Peter's ability to make choices is minimally impaired (see Table 4). He requires some supervision and cuing when it comes to decision-making (InterRAI-ID, p. 2). Peter wakes up in the morning by himself unless he has an early appointment. He also usually chooses when he wants to go to bed (Staff Interview). Peter chooses what he wants to eat and

where he wants to go in the community (Staff Interview; Quality of Life Questionnaire; Observation). He often chooses his casual leisure activities (e.g. TV, walks, etc) and the type of household chores he wants to help out with (Quality of Life Questionnaire, p. 4; see Table 2). Peter had little choice about the type of house and the type of neighborhood he moved into. However he makes his own decisions about his space for privacy as he has full access to different rooms in his house (Quality of Life Questionnaire, p. 3). He rarely makes decisions about his physical health, hygiene, and body care. He does not decide who his friends are and when to spend time with his friends or family. He does not have too many choices when it comes to taking courses and finding employment in the community (Quality of Life Questionnaire, p. 4).

When asked if he wanted changes in his living arrangements, daily routines, recreational activities, or employment status, he could not respond (InterRAI-ID, p. 2). According to his primary support staff,

> Peter was never in an environment that he had full access to in the past or involved with choice making. He now has full access to his home, particularly the kitchen where he actively prepares his own meals with minimal supervision (keeping mind what is important for him) this is a major step for Peter considering that food at one time seemed to trigger some behaviours (Staff Interview, pp. 5).

The data indicate that opportunities for choice making in Peter's life in the community residential setting have increased in some aspects of his life compared to the institutional levels. He makes a lot of decisions about his daily routines, leisure activities, community outings, social interactions, and household chores. However there are still areas in his life in which the opportunity for choice making remains low including his living

arrangements, looking after his physical health, his education and employment. The support staff or others typically make these decisions for him.

Angie's pre data for choice making. Before the transition, Angie's ability to make choices was identified as severely impaired based on InterRAI-ID reports (see Table 4). She rarely made any decisions in her day-to-day life (InterRAI-ID, p. 2). She had limited choice when it came to the type of food she ate. She was on a level 1 pureed diet with thickened juice or water due to her swallowing difficulties (Essential Elements Plan, p. 4; File review). Angie is non-verbal and she could not respond when asked if she preferred changes in her living arrangements, daily routines, recreational activities, and employment opportunities (InterRAI-ID, p. 2). It is difficult to measure the extent of her choice making based on institutional records but according to the InterRAI-ID, Angie was not presented with many choices throughout the day.

Angie's post data for choice making. At the new house, Angie communicates her likes and dislikes by facial expressions and body language. In the morning, Angie wakes up when she wants to and at night she initiates bedtime herself by fidgeting, crying or falling asleep in her chair (Staff Interview). Staff only wake her up if she has an appointment in the morning (Staff Interview). There are some opportunities for her to make choices about the food she eats as staff try new combinations to determine whether she enjoys them (Staff Interview). There are also opportunities for her to make decisions about her hobbies, leisure activities, and places she likes to visit in the community (Quality of Life Questionnaire, p. 4-5; see Table 2). She does not make her own decisions about looking after her physical health, hygiene, doing household work, where she lives, and her space for privacy (Quality of Life Questionnaire, p. 3). She also does not make

choices about her social interactions, spending time with her family and friends, education, and employment (Quality of Life Questionnaire, p 3-5). Although the scores on the InterRAI-ID have not changed from pre to post deinstitutionalization, and her choice making ability remains severely impaired (InterRAI-ID, p. 2), she does make choices in some areas of her life and certainly communicates her preferences through facial expressions. She decides what her leisure activities and hobbies are and the places she likes to go in the community. Frequency of choice making is quite low in other aspects of her life.

Jane's pre data for choice making. Although Jane's decision making was scored as severely impaired in the InterRAI-ID (see Table 4), data from the file review suggest that she had some opportunities to make choices in her daily life. Jane enjoyed listening to music, especially 50s and 60s country and jazz. She also owned a radio when she was living at the institution, and chose what stations she wanted to listen to. At the institution, there were weekly dances and monthly concerts for the residents. Jane usually chose to attend the dances and the concerts. Jane was sometimes given light chores like carrying her own laundry basket to her room. She had the opportunity to choose whether or not she wanted to help out with the chores (File review; Essential Elements Plan, p. 5). Jane was asked if she preferred any changes in her living arrangements, daily routines, recreational activities, or employment status, and she responded "no" although it is unclear whether she comprehended the questions. In general, Jane had limited opportunities for choice making while living at the institution.

Jane's post data for choice making. The scores on the InterRAI-ID from pre to post deinstitutionalization have changed from severely impaired choice making ability to

moderately impaired (InterRAI-ID, p. 2; see Table 4). In the morning staff normally awakes Jane but she usually initiates her bedtime by taking staff to her room and lying on her bed (Staff Interview). Jane makes choices on a daily basis about the places she goes to in the community, her daily routines, what clothes she wears, the type of household work she does, her leisure activities, and social interactions (Quality of Life Questionnaire, p. 4-5; Staff Interview; Observation). On the other hand, she does not directly make decisions about her living arrangements, the food she eats, her physical health and hygiene (Quality of Life Questionnaire, p. 2-3; see Table 2). She does not choose who her friends are or whether she wants to spend time with them or with her family. She also does not make her own decisions about having meaningful work or receiving any type of training in the community (Quality of Life Questionnaire, p. 3-4). Overall, the extent of opportunities for choice making has increased slightly for Jane compared to when she was at the institution, as she is able to make frequent choices about her daily routines, community leisure activities, and types of household chores she carries out. However, her opportunities for choice making are still at a low level.

Discrepancy Analysis

Peter's Essential Elements Plan. A secure structured living environment with his own bedroom and, if possible, an ensuite bathroom were recommended for Peter. It was recommended that they install alarms on front doors, and fences around the backyard. It was also recommended that Peter move into a safe and traffic free location where he could go for walks outside (Essential Elements Plan, p. 8). It was insisted in the plan that Peter be taken out for walks regularly and that he needs close supervision when out in the community (Essential Elements Plan, p. 8). The plan emphasized that Peter

needs a fulltime day program where he is taught new skills. In terms of professional services, it was recommended that he continue with regular visits to a physician, dentist, and optometrist. Peter's immunizations need to remain current according to Public Health Guidelines and his medications require regular monitoring. Peter's behavioural problems should be closely monitored and if an escalation occurs, he needs to be referred to psychological and/or behavioural services.

Peter's placement. The house that Peter lives in now has alarms installed on doors for safety and a fully fenced backyard. Peter has his own bedroom although the room does not have an ensuite bathroom (Observation; Staff Interview). The furniture in his room is sparse due to his history of throwing furniture (Observation; Agency Administrative Staff Interview). The house is located in the country alongside a highway and there are no sidewalks on either side of the highway. This makes it challenging for Peter to go on walks especially with his history of elopement. Nonetheless, Peter goes on frequent community outings such as to restaurants, shopping, movies, etc. He also volunteers at a local food bank. He comes into regular contact with other community members. Although he usually does not approach others in the community, when they interact with him, he seems to enjoy it (Staff Interview; Observation). Some staff from institution A were hired to work at the house so he had a sense of familiarity when he first moved in. The staffing ratio is three to six during the day and one to six at nighttime. When Peter first moved in, he had two overnight staff initially but now, due to a decrease in his problem behaviours, the staffing has been decreased to one overnight. For his community outings, transportation is provided and staff accompanies him at all times. The Ontario Disability Support Program (ODSP) income provides him with sufficient

funds for small purchases while he is out in the community (Transitional Plan). Peter visits his physician every three months for medication reviews and other health related issues and his immunization is up-to-date. He also visits his dentist every three months for cleaning and his optometrist once a year. He has a psychologist and a behaviour consultant to whom he has access if needed. When he first moved into the house, there was an escalation in his problem behaviours and he was referred to behaviour management services. He is currently on a maintenance program, as his problem behaviours are no longer an issue.

Peter's discrepancy analysis. Peter's placement has been consistent with the Essential Elements Plan for the most part. One discrepancy is the location of the new house. Considering Peter's history of elopement, the plan recommended that he move into a safe and traffic-free location where he can go for walks outside his house. Peter's new house is located in the country alongside a highway with no traffic lights or sidewalks. This makes it unsafe for him to go for walks outside his house. In the plan it was recommended that Peter attend a fulltime day program to help him learn new skills that he can apply in his daily life and prepare him for future employment opportunities. Peter does not attend any day programs outside his home. According to the staff, they run a day program in the house with all the residents. The format and the effectiveness of the day program remain unclear.

Angie's Essential Elements Plan. The recommendations made in the plan for Angie included an accessible home, appropriate bathing system with trolley, custom wheelchair and regular maintenance on her wheelchair (Essential Elements Plan, p. 10). It was suggested that all staff receive training on Rett Syndrome and Dysphasia and also

receive training around lifting and transfer techniques as they apply to Angie (Essential Elements Plan, p. 10). In terms of community leisure activities and integration, it was recommended that Angie continue with things she enjoys such as walking, riding, attending social functions, joining a faith based group and attending church (Essential Elements Plan, p. 10). Angie requires annual assessment by a physician and semi-annual visits with a dentist. She also needs to continue visiting an optometrist every two to three years. Her immunizations should remain current according to Public Health Guidelines. Angie requires visits with an occupational therapist (OT) and an environmental assessment of her new living arrangements by the OT. It was recommended that the new agency obtain the services of a certified aromatherapist and provide Angie with access to a hydrotherapy facility. It was suggested that she receive hydrotherapy on a weekly basis.

Angie's placement. Angie lives in a fully accessible house located on a large country lot. She has her own bedroom with large windows designed to let light in. Assistive devices were ordered to accommodate Angie including a custom wheelchair and tub with a ceiling mount device that assists staff with lifting her to and from her wheelchair (Facility Planners Interview; Transitional Plan). Aside from the television in the living room, Angie has her own television set in her bedroom. There is a large fenced backyard where Angie spends a lot of time during the summer months. There is also an elevator built in the house providing her access to and from the garage and the lower level of the house (Discrepancy Analysis; Facility Planners Interview; Observation). Angie's sister, Mary, is quite pleased with the setting (Family Interview; Facility Planners Interview). There are six residents and three support staff during the day and one overnight staff (Staff Interview). The agency has hired some of the staff from institution

A to support individuals living at Angie's house, which helped with her transition. Sufficient training has been provided for the staff and dysphasia training is being planned (Staff Interview). To transport her to and from community outings, a van with a wheelchair lift has been purchased by the agency. A staff member accompanies Angie at all times when she is in the community (Transitional Plan; Staff Interview; Observation). There are no sidewalks around her house making it difficult for her to go for walks. The staff use a van to drive her to a park every time she wants to go for a walk (Observation; Staff Interview). Angie goes on community outings on a regular basis including going on shopping trips, to movies, parks, and church (Staff Interview). Angie visits her physician every three months for medication reviews and has complete annual physical assessments. She visits her dentist every three months and her optometrist once a year. She has access to an occupational therapist who is currently working on range of motion exercises with Angie and she also has access to regular hydrotherapy. She also sees a gynecologist for problems with her menstruation.

Angie's discrepancy analysis. Angie's actual placement is very consistent with the Essential Elements Plan with some minor discrepancies between the two. In the plan, it was recommended that Angie go on walks regularly. However, she lives in the country and there are no sidewalks around her house, which makes it impossible for her to wheel outside. It was also suggested that all staff at the new house receive Dysphasia training and this has not happened so far. Angie has access to all the recommended professional services included in the plan.

Jane's Essential Elements Plan. According to the Essential Elements Plan, Jane

needs her own bedroom on the main floor with no stairs to her room because of difficulties with her gait and vision. Due to her high-pitched screaming, if possible her bedroom needs to be soundproof so the noise does not disturb her housemates. Also if possible, alarms should be installed on doors for safety reasons (Essential Elements Plan, p.16). She needs to have access to a wheelchair when she goes on long outings as she gets tired and is unable to walk for long periods of time (Essential Elements Plan, p. 16). Jane has lost all her teeth but she requires regular visits to her dentist to ensure on-going gum care. She also needs to have regular access to her physician and requires regular monitoring of her medications. Her immunization needs to be kept current and she also requires routine PAP tests. Referral to a speech pathologist was also recommended. It is important that she is referred to behaviour management services to monitor her problem behaviours and develop plans for staff to implement. It was recommended that Jane be integrated with her faith community by joining Friendship Groups and attending social events within the faith community. Participation in various leisure activities was also recommended (Essential Elements Plan, p. 16-17).

Jane's placement. Jane lives in a two-story house located in the country with 5 other individuals. She has her own bedroom on the main floor and her bed was from institution B was moved to her new home for her comfort. There are two separate living rooms and a dining room that is connected to the kitchen through a built-in gate. The house also has a backyard, which is enjoyed by the residents in the summertime (Discrepancy Analysis; Staff Interview; Facility Planners Interview). In order to ensure her safety, gates were installed on all the stairways, padding was installed around the windows, and she is provided with adequate staffing when she is out in the community

(Facility Planner Interview; Agency Administrative Staff Interview). The staffing ratio is three to six during the day and one to six overnight. However, when Jane goes on an outing, especially swimming, it is preferable that she has two support staff with her, which is not always a possibility (Staff Interview; Facility Planners Interview). Jane goes out daily on van rides and different places in the community such as restaurants, parks, shopping, and local attractions (Staff Interview). Jane moved in with a restraining chair but soon after she did not need it. A behaviour consultant was consulted to assist staff with managing her behavioural challenges. The consultant provided training for staff and met with staff and the house manager every two weeks to review behavioural plans and the data collected by staff (Agency Administrative Staff Interview; CMSI). Jane has annual visits with her physician for complete physical assessments. She does not see a dentist because she no longer has teeth. She has seen an optometrist in the last year and also had a hearing exam in the last two years. Her immunizations are up-to-date. She currently does not have access to a speech pathologist.

Jane's discrepancy analysis. Jane's living space is consistent with what was recommended in the plan. The only minor discrepancies are that there are no alarms installed on doors to prevent elopement and her bedroom walls are not soundproof was although this was suggested in the plan. Her neighbors have complained about her screaming therefore it is predicted that the screaming disturbs her housemates as well. Staffing ratios are not always ideal for some community outings such as swimming. It is not possible for the agency to provide her with two support staff while she is on an outing alone without her other housemates. Jane currently has access to all community-based professional services except for a dentist and a speech pathologist. She does not have

access to a dentist because she has lost all her teeth and staff are responsible for her gum care.

Summary of Results

Research question #1: What is the degree of family involvement of former facilities residents? Prior to transition, two of the participants rarely received visits from their family members. The frequency of visits was not related to geographical distance as one family member lived in the same city about 1 hour away from the institution and in the other case the family lived in a different city quite far from the facility. The third participant received visits from his family members a few times a year. The frequency of family contact following deinstitutionalization has increased in two cases, although for one of them it was a slight increase, and for the third participant the frequency of contact has remained the same. In one of the cases where there was an increase in family interactions, the location of the new residence is a lot closer to the family members' house. There are opportunities for the participants to spend time with their family members however, they do not decide if and when they want to spend time with their family. Family members and staff usually arrange these visits. Since all three participants have communication deficits, they are unable to have phone or e-mail interactions with their family. In all cases however, there is good communication with the agency staff via phone or email and the family members are updated regularly on how the participants are doing. While living at the institution, none of the participants visited or stayed overnight at their family members' house except for one of the participants who was taken to see her mother before she passed away. After relocation to the community residences, only one of the participants has visited her family member at their house spending time and

sharing meals with them. Following discharge, none of the participants have stayed overnight at a family member's house.

It is difficult to measure the exact levels of family involvement prior to deinstitutionalization. Data from the file review suggests that families have all been involved in their family member's life either by visiting or staying informed by keeping contact through staff. All family members chose to participate in the planning process. They attended meetings with the planners either in person or via teleconferencing, visited the home and expressed their needs and voiced their concerns. In one case, the family members clearly preferred some agencies to others and their wishes were taken into consideration. Other than the frequency of visits, it is unclear if the degree of family involvement and support has changed from before to after deinstitutionalization.

Research question #2: To what extent are there opportunities for participation in community leisure activities and interactions with community members? When living at the institution, the majority of outings were done inside the facility. They went on walks, swimming, attended church and social events at the institution. Occasionally they went on community outings outside the facility (e.g., bus rides, camping trips, etc). With relocation to the community, there has been an increase in the frequency and variety of community outings for the residents. In the community residential setting, there are increased opportunities for them to go on different community outings and they choose the types of outings they prefer. Being able to participate in different community leisure activities is very important for all participants and they are all very happy with the frequency and variety of these activities. They are at ease participating in planned activities in the community and interacting with other

community members. There are opportunities for social interaction for the participants. Although the participants rarely approach members of the community independently, when community members approach them the interactions are generally positive. Social interactions are very important for one participant, somewhat important for one and not important for the other participant. In all three cases, they are accepted by their immediate neighborhood, however, in one case a neighbor has complained about the participant's frequent screaming. They have access to community-based social and medical services as well as community buildings such as libraries, recreational facilities, restaurants, shopping malls, etc. Participants are unable to indicate verbally if they would prefer any changes in the type, frequency, or variety of community leisure activities. Some support staff believe that country living at times limits the extent of community integration for the participants. They do not come into contact with other members of the community simply by going outside the house and they need to drive in some cases long distances to get to a community-based facility. Also the quantity and variety of leisure activities that are available in the community are limited.

Research question #3: To what extent are there opportunities for choice making? Although it is difficult to measure the actual levels of choice making by reviewing the individuals' institutional files, the review suggests that the nature of the institutional living did not allow residents the opportunity to make frequent choices in their day-to-day lives. The residents had to wake up and go to bed at certain times and food was served at specific times. The participants had some choice in leisure activities such as picking the type of music they wanted to listen to, where they wanted to go and what they wanted to do in their spare time, although the options were often limited.

Following deinstitutionalization, all three participants are offered more choices living in a more flexible environment. They no longer have to wake up at a specific time, choose what they want to do with their leisure time and the types of community outings they want to go on. Two of the participants have some choices in the food they eat, one of them often helps prepare his meals and the other participant, who is non-verbal and non-ambulatory, communicates her likes and dislikes through her facial expressions. The third participant, who lives in a different house from the other two, rarely makes decisions about the food she eats. In two out of three cases, the individuals are able to help out with the household chores and they have the opportunity to choose the type of chores they want to do. They have frequent choices with regards to their daily routines and hobbies. On the other hand they have little choice in their physical health, hygiene, education and employment status. They also have little say about their living arrangements including the type of house and the neighborhood in which they live, and the people with whom they live. The participants do not make decisions about who their friends are and spending time with their family and friends. Overall, although participants' choice making has increased from its institutional levels, it still remains low.

Research question #4: What is the degree of discrepancy between the actual placement and the EEP? What are the types of supports needed to adapt to the plan? The placements have been consistent with the Essential Elements Plan for the most part with some minor discrepancies. In terms of the setting, each participant has his/her own bedroom and various measures have been taken to ensure the residents' safety and security such as installing alarms on doors, fences around the backyard, gated stairs, padding around the windows, and custom tubs. For one participant the plan suggested an

ensuite bathroom, which was not possible in the actual setting and for another participant, they recommended alarm installations on doors which was not carried out in the new house. The plans for all three participants emphasize the fact that they enjoy going for walks regularly and yet both houses are located in the country where there are no sidewalks making it difficult for them to walk around their neighborhoods. All participants have access to all recommended professional and medical services except for one of the participants who does not have access to a speech pathologist and a dentist as was suggested in the plan. This participant has lost all her teeth and staff are responsible for her gum-care. It is believed that she will benefit from a speech pathologist, but the agency has not been able to obtain one.

The Essential Elements Plan for all three people briefly recommends participation in various community activities. This is where the actual placement can differ from the plan due to a change in the environment and an abundance of opportunities for the individuals to participate in different social and community activities. The staffing ratios have been consistent with what was recommended, however sometimes more staffing is needed for certain participants when they are on outings and it is not always possible for the agency to accommodate that.

Discussion

The present case analysis was part of an evaluation of the current Facility Initiative in Ontario. In this study, the experiences of three individuals with ID who were transitioned from institutional facilities to community-based settings in the last four years were examined. This study focused on changes in the QOL of these individuals more specifically their family contact, community involvement, and choice making following

their relocation. In addition, their current placement was compared with the recommendations made in the Essential Elements Plan. In this section the findings of the study, its strengths, limitations, and suggestions for future research are discussed.

Family Involvement

The findings of this study indicate an increase in the frequency of family contact following deinstitutionalization for two of the participants (Angie and Jane) and no change in the frequency of these contacts for the third participant (Peter) who had consistent family contact prior to his move. The two participants who have more frequent interactions with their family members since the transition rarely received visits from their families while living at the institutions. Since their transition, they have received more visits from family members, although for one of these individuals (Angie) there has been only a slight increase in the frequency of family visits. Peter has approximately the same amount of contact with his family as he had in the institution. This could be due to a higher frequency of family contact before transition as compared to the other two participants. These findings are consistent with the literature on family involvement that reports increases in frequency of opportunities and actual contact with family members following deinstitutionalization (Conroy, Spreat, Yuskauskas, & Elks, 2003; Cummins & Dunt, 1988). According to Conroy et al. (2003), before relocation a large percentage of participants had no family contact and following relocation only half of those individuals did not have interactions with family members.

Even though there are some increases in the frequency of family visits, the degree of involvement has not changed compared to before discharge. Based on the institutional records, family members of all three participants were involved in their lives before

relocation by being their SDMs, keeping contact with staff, and participating in their transitional planning. They were all similarly involved in their family member's planning process by attending meetings with planners, expressing their concerns for the participants' safety and well-being, contributing to the Essential Elements Plans, and visiting the new homes when their family members moved in. They have all expressed great satisfaction with the new living arrangements and the transition in general. According to Heller, Bond, and Braddock (1988), there is an association between family involvement and more positive attitudes towards the deinstitutionalization process. They found one of the main predictors of family satisfaction with the transition to be the degree of involvement with the resident (Heller, Bond, & Braddock, 1988). This finding certainly applies to all three participants in this study, as all families believe services have improved since the transition.

Due to limited speech and communication skills, none of the participants is able to communicate with their family members via telephone, e-mail, or letters. All three family members have consistent communication with the agency and the support staff. The families determine the frequency of these interactions. Some prefer more frequent updates whereas others are contacted for special occasions (i.e. birthdays, Christmas, Thanksgiving, etc.) or if there are any concerns with the individual. Since relocation to the community, only one of the participants has visited her family's house. It would be possible for the agencies to arrange visits to the family members' homes if families were in support of home visits. The reasons for not having home visits were not revealed. Keeping all this in mind, other than visits every few months, there are no direct interactions with the family members. It can be concluded that even though the frequency

of family visits has increased for some individuals, family interactions are still infrequent. Longitudinal research is needed to determine whether the frequency of these interactions will increase over time. It would also be interesting to find out whether other family members will start to become involved in the participants' lives over time.

Community Engagement

One consistent finding across all participants is that the frequency and range of participation in community leisure activities has increased following deinstitutionalization. Although they participated in different leisure activities at the institutions, the majority of these activities took place inside the facilities. Living in the community has provided more opportunities for these individuals to go on different community outings. These results are consistent with the findings of a study by Baker (2007) who measured the community participation of people with ID before and after their transition into the community and compared them to individuals with ID who were living in the community when the study began. Baker found increases in the frequency and variety of community activities following relocation, however community participation remained low when compared to other people with ID living in the community.

Choice Making

The results of the present study suggest that there are increased opportunities for community contact and social interactions following relocation. Participants did not come into frequent contact with other members of the community outside the facility. Community living provides more opportunities for social interactions. When participants go on community outings (i.e. shopping malls, restaurants, recreational facilities, etc.),

they come in contact with other members of the community. Although they usually do not initiate interactions with other community members, when they are approached the interactions are positive. Consistent with the findings of this study, increases in community activities and social interactions of individuals have been reported in the literature. According to Cummins and Dunt (1990), deinstitutionalization results in a more frequent and varied range of community-based social activities for the former residents. Yet it is important to keep in mind that the community participation and interactions of these individuals continues to be very low compared to the general population and individuals with ID who have been living in the community for longer periods of time.

All three of the participants in the present study are currently residing in a country setting. The data from interviews with support staff and facility planners suggests that living in the country could stand in the way of the participants' community integration by making it more difficult for them to access certain community-based activities and to come in contact with other community members. Future research should explore the differences in community integration between individuals living in a country setting and those living in a city.

In the present study two of the participants (Peter and Jane) had higher adaptive skills compared to the third participant (Angie). According to Baker (2007), residents with higher adaptive scores have more community involvement. This finding applies to one of the participants in this study. Peter has a wide range of community activities in which he participates such as going to restaurants, shopping, movies, and playing sports. He is also the only participant who does volunteer work. Of all three participants, his

community involvement has increased the most since his days at the institution. Perry and Felce (2005) found two factors associated with community involvement to be adaptive skills and the amount of attention received from staff. Although Peter and Jane's adaptive functioning are at a similar level, they live in different settings. The setting and the support staff could possibly have an effect on the participants' community engagement.

Based on the results of the present study, another factor that can have an effect on community participation is the level of maladaptive behaviours. Individuals with high rates of problem behaviours are often not able to participate in certain social activities involving other community members due to safety issues. Jane has a history of behavioural challenges. Although she currently participates in community social activities, her behavioural issues often restrict her community involvement. When she engages in problem behaviours, she might not participate in scheduled activities, or might be returned to the house or removed from situations where there are other community members present. More research is needed to determine to what extent community engagement is affected by the presence of behavioural issues and how effective are behavioural interventions in increasing community involvement.

The results of this study suggest that the participants' choice making has increased in the community compared to the institutional levels. These findings are consistent with the literature on choice making. Young and Ashman (2004b) reported that choice making increased significantly following deinstitutionalization. In a different study, Stancliffe and Abery (1997) compared the opportunities for choice making for individuals who were transitioned into the community with those who stayed at the institution. They found the opportunities for choice making increased significantly for the

relocated individuals. However, these choices were found to be limited as compared to the other members of the community. These findings are similar to the results of the present study. Despite increases in the opportunities for choice making following relocation, there are still areas of the individuals' lives where they are offered few choices. They do not make choices about where they live, with whom they live, and who their friends are. They do not make decisions about their physical health, hygiene, and whether or not they wish to be employed. According to Dagnan, Ruddick, and Jones (1998), opportunities for choice making increase when individuals first move into the community and then decrease after a few years of living in that environment due to the regularity of daily activities and staff familiarity with the residents.

Shogren, Faggella-Luby, Bae, and Wehmeyer (2004) did a review of the existing literature on the impact of choice making on problem behaviour. The findings of this review suggest that choice making has a positive impact on QOL and the complexity of behavioural problems displayed by individuals with ID. According to the literature, more opportunities for choice making are associated with lower rates of problem behaviour within community residential settings (Romaniuk & Miltenberger, 2001). In the present study the frequency of problem behaviours has been reduced as compared to the institutional levels, more specifically for Peter. The relocation initially resulted in an increase in problem behaviours and over time it decreased in Peter's case to near zero levels. As suggested in the literature, the reduction in maladaptive behaviours in this study could be associated with increased opportunities for choice making among the former institutional residents.

Discrepancy Analysis

A few studies report that residents with higher IQ and higher levels of adaptive functioning are more likely to engage in choice making (Perry & Felce, 2005; Stancliffe & Abery, 1997). In the present study, two of the participants scored higher in adaptive functioning than did the third. As compared to the participant with lower adaptive scores, there were more opportunities for decision making for one of these two participants (Peter) but only slight improvements for the other (Jane). This could potentially be due to the differences in the type of settings they reside in.

The results of this study indicate that the Essential Elements Plan has been followed for the most part by the receiving residential agencies. There are a few discrepancies between the plan and the actual placement identified in this study. The plan does a complete job of describing the ideal type of living arrangements for each individual. There is great focus on the individual's safety, comfort, and access to community-based activities when it comes to planning an ideal setting for each individual. One of the main discrepancies found across all three participants is the location of the houses to which the participants were transferred. It was stated in the plans that these individuals enjoy going outside for walks and that staff should take them out for walks on a regular basis. However, living in rural settings makes it difficult for them to go for walks in their immediate neighborhoods due to safety issues. One of the participants (Peter) has a history of elopement thus it was recommended in his plan that he should be moved into a safe and traffic-free location. Instead, he was moved into a house located on a highway with no traffic lights or sidewalks. Peter has eloped from the house several times and once was found on the other side of the highway. The other

participant (Angie) who lives in the same house is non-ambulatory and cannot wheel outside since there are no sidewalks. Future transitions should accommodate the residents' need to live in neighborhoods that they can easily access for their leisure activities.

The majority of recommended professional and medical services have been provided for the participants. For two of the participants (Peter and Angie), there are no structured day programs available outside their living space and Jane has been removed from her day program due to her behavioural issues. There is a need for more day programs with a focus on teaching these individuals new skills to be able to attain more independence. For example, Peter currently volunteers at a food bank and could potentially hold a paid job in the future. A program that is tailored to his needs could provide him with the right skills and opportunities to be more independent and to find paid employment if he so chooses.

The facility planners had meetings with the family and staff. They also observed the individuals getting to know their strengths, challenges, likes and dislikes. The plans captured the needs of the individuals at the time of the transition. According to one of the planners, "it is a snapshot of the person in time. It is not meant to be a static document". Each individual evolves with time as a result of changes in their environment and the emergence of different opportunities. The plans need to reflect these changes and evolve with the individual over time. The facility planners did not know the individuals prior to their transition and were contracted to carry out the planning often within short periods of time. In some cases, their contracts ended prior to the three-month follow up with the

residents. There is a need for more long-term evaluation and follow up to examine the appropriateness of the living arrangements for each individual.

Strengths and Limitations

There are several strengths of this study that must be considered. First, the sample included participants representing a cross-section of the population representing key factors such gender, behavioural challenges, medical needs, and psychiatric issues. Second, the study employed multiple informants and various methods of data collection (e.g., standard measures, interviews, and observations) to ensure reliability of the data. Finally, the study's design and data collection procedure allowed for an in-depth examination of the life experiences of the participants in their new community-based settings as compared to the institutions they lived in previously.

On the other hand, there are some limitations to the design and execution of the study that must be acknowledged. First, due to the lengthy process associated with obtaining ethics clearance and completing participant recruitment, it was not possible to observe the individuals at the institutions before their transition. By the time the study began, the last remaining institutional facilities had closed and all participants had transitioned to their new community homes. The only measure that was used before and after relocation was the InterRAI-ID. Having the same full set of pre and post measures would have increased the validity of the results of the present study. Future research needs to follow these individuals over time to examine any changes in their medical, psychological, behavioural and social needs, and changes in their overall QOL.

Second, the number of participants included in this study was small. Having more participants strengthens the results and allows for more comparisons across different

people, environments, and services. Third, two of the participants were from the same institutional facility and are currently living in the same house. At the new residence, they share the same support staff, agency Executive Director, and they even shared the same facility planner. This skews the data to some extent considering that there are only three participants included in this study. Finally, due to the participants' communication deficits, measures rely heavily on feedback from third parties.

Conclusions

Although the transitional process and community life experience is unique for each individual, some similarities were found across the participants. The results of this study suggest that there are increases in family interactions, community involvement, and choice making following relocation to the community. However, these improvements in quality of life still remain minimal. This study also found few discrepancies between the Essential Elements Plans and the actual community placements of these individuals. The EEPs are useful documents as the individuals first move in the community. They contain historical accounts of the individuals, and provide information on who they are and the nature of their likes and dislikes. What these plans do not tell us is what the future holds for them. The possibilities are endless. The rest of their journeys will depend on how the community embraces and supports them.

References

Allen, D. (1989). The effects of deinstitutionalisation on people with mental handicaps: A review. *Mental Handicap Research, 2,* 18-37.

Anglin, B. & Braaten, J. (1978). *Twenty-five years of growing together: A history of the Ontario Association for the Mentally Retarded.* Toronto: Canadian Association for the Mentally Retarded.

Baker, P.A. (2007). Individual and service factors affecting deinstitutionalization and community use of people with intellectual disabilities. *Journal of Applied Research in Intellectual Disabilities, 20,* 105-109.

Bruininks, R. H., Meyers, C. E., Sigford, B. B., & Lakin, K. C. (1981). *Deinstitutionalization and community adjustment of mentally retarded people.* Washington, DC: American Association on Mental Deficiency.

Bruininks, R. H., Woodcock, R. W., Weatherman, R. F. & Hill, B. K. (1996). *Scales of independent behavior-revised.* Itasca: IL. Riverside.

Conroy, J. & Latib, A. (1982). *Family impacts: Pre-post attitudes of 65 families of clients deinstitutionalized.* Pennhurst Longitudinal Study, Temple University Developmental Disabilities Center, Philadelphia.

Conroy, J., Spreat, S., Yuskauskas, A., & Elks, M. (2003). The Hissom closure outcomes study: A report on six years of movement to supported living. *Mental Retardation, 41,* 263-275.

Cullen C., Whoriskey M., Mackenzie K., Mitchell W., Ralston K., Shreeve S. & Stanley A. (1995). The effects of deinstitutionalisation on adults with learning disabilities. *Journal of Intellectual Disability Research 39,* 484-494.

Cummins, R.A., & Dunt, D. (1988). Evaluation of a deinstitutionalization program in Australia: The St. Nicholas project. *International Journal of Rehabilitation Research, 11,* 395-396.

Cummins, R.A., & Dunt, D. (1990). The deinstitutionalisation of St. Nicholas hospital: II lifestyle, community contact and family attitudes. *Journal of Intellectual & Developmental Disability, 16,* 19-32.

Cummins, R.A., Polzin, U., & Theobald, T. (1990). The deinstitutionalisation of St. Nicholas hospital: IV a four-year follow-up of resident life-style. *Journal of Intellectual & Developmental Disability, 16,* 305-321.

Dunt, D., & Cummins, R.A. (1990). The deinstitutionalisation of St. Nicholas hospital: I adaptive behaviours and physical health. *Australia and New Zealand Journal of Developmental Disabilities, 16,* 5-18.

Dagnan, D., Ruddick, L., & Jones, J. (1998). A longitudinal study of the quality of life of older people with intellectual disability after leaving hospital. *Intellectual Disability Research, 42,* 112-121.

Emerson, E. (2004). Deinstitutionalisation in England. *Journal of Intellectual & Developmental Disability, 29,* 79-84.

Emerson, E., & Hatton, C. (1996). Deinstitutionalization in the UK and Ireland: Outcomes for service users. *Journal of Intellectual & Developmental Disability, 21,* 17-37.

Eyman, R. K., Borthwick-Duffy, S. A., Call, T. L. & White, J. F. (1988). Prediction of mortality in community and institutional settings. *Journal of Mental Deficiency Research, 32,* 203-213.

Eyman, R. K., Grossman, H. J., Chaney, R. H., & Call, T. H. (1990). The life expectancy of profoundly handicapped people with mental retardation. *New England Journal of Medicine, 323,* 584-589.

Felce, D., & Emerson, E. (2001). Living with support in a home in the community: Predictors of behavioural development and community activity. *Mental Retardation and Developmental Disabilities Research Reviews, 7,* 75-83.

Felce, D., Mair, T., de Kock, U., & Saxby, H. (1985). An ecological comparison of small community-based houses and traditional institutions – 2: Physical setting and the use of opportunities. *Behavioural Research Therapy, 23,* 337-348.

Feldman, M. A., Atkinson, L., Foti-Gervais, L., & Condillac, R. (2004). Formal versus informal interventions for challenging behaviour in persons with intellectual disabilities. *Journal of Intellectual Disability Research, 48,* 60-68.

Fine, M.A., Tangeman, P.J., & Woodard, J. (1990). Changes in adaptive behavior of older adults with mental retardation following deinstitutionalization. *American Journal on Mental Retardation, 94*, 661-668.

Griffiths, D. (2007a). *Agency administrative staff interview.* Unpublished questionnaire, Brock University, St. Catharines, Ontario, Canada.

Griffiths, D. (2007b). *Discrepancy analysis.* Unpublished questionnaire, Brock University, St. Catharines, Ontario, Canada.

Griffiths, D. (2007c). *Facility planners interview.* Unpublished questionnaire, Brock University, St. Catharines, Ontario, Canada.

Griffiths, D. (2007d). *Family interview.* Unpublished questionnaire, Brock University, St. Catharines, Ontario, Canada.

Griffiths, D. (2007e). *Front line staff interview.* Unpublished questionnaire, Brock University, St. Catharines, Ontario, Canada.

Griffiths, D. (2007f). *History questionnaire.* Unpublished questionnaire, Brock University, St. Catharines, Ontario, Canada.

Griffiths, D. (2007g). *Observation sheet.* Unpublished questionnaire, Brock University, St. Catharines, Ontario, Canada.

Griffiths, D., Owen, F., Hamelin, J., Feldman, M., Condillac, R., & Frijters, J (2009). *Literature review for the facility initiative: The end of the era of provincially operated facilities for persons with intellectual disabilities in Ontario.* Unpublished manuscript, Brock University, St. Catharines, Ontario, Canada.

Hauber, F. A., Bruininks, R. H., Hill, B. K. Lakin, K. C. & White, C. C. (1982). *National census of residential facilities: Fiscal year 1982* (Project Rep. No. 19). Minneapolis: University of Minnesota, Department of Educational Psychology, Center for Residential and Community Services.

Heller, T. (1988). Transitions: Coming in and out of community residences. In M. Janicki, M. W. Krauss, & M. M. Seltzer (Eds.), Community residences for persons with developmental disabilities: Here to stay (pp. 149-158). Baltimore: Brookes.

Heller, T., Bond, M.A., & Braddock, D. (1988). Family reactions to institutional closure. *American Journal on Mental Retardation, 92(4),* 336-343.

Heller, T., Miller, A. B., Hsieh, K., & Sterns, H. (2000). Later-life planning: Promoting knowledge of options and choice-making. *Mental Retardation, 38,* 395–406.

Hill, B. K., & Bruininks, R. H. (1984). Maladaptive behavior of mentally retarded individuals in residential facilities. *American Journal of Mental Deficiency, 88,*

380-387.

Holburn, S., Jacobson J., Schwartz, A., Flory, M. & Vietze, P. (2004). The Willowbrook Futures Project: a longitudinal analysis of person-centered planning. *American Journal on Mental Retardation 109,* 63-76.

Holburn, S. & Christine D. C. (2007). Excessive positivism in person-centered planning. *Research & Practice for Persons with Severe Disabilities, 32,* 167-172.

Janssen, C.G.C., Vreeke, G.J., Resnick, S., & Stolk, J. (1999). Quality of life of people with mental retardation: Residential versus community living. *British Journal of Developmental Disabilities, 45,* 3-15.

Johnson, K., & Traustadottir, R. (Eds.). (2005). *Deinstitutionalization and people with intellectual disabilities: In and out of institutions.* Philadelphia: Jessica Kingsley Publishers.

Kern, L.,Vorndran, C. M., Hilt, A., Ringdahl, J. E., Adelman, B. E., & Dunlap, G. (1998). Choice as an intervention to improve behavior: A review of the literature. *Journal of Behavioral Education, 8,* 151-169.

Kim, S., Larson, S.A., & Lakin, K.C. (2001). Behavioural outcomes of deinstitutionalisation for people with intellectual disability: A review of US studies conducted between 1980 and 1999. *Journal of Intellectual & Developmental Disability, 26,* 35-50.

Lancioni, G. E., Bellini, D., & Oliva, D. (1993). Building choice opportunities within a robot-assisted occupational program: A case study. *Behavioral Residential Treatment, 8,* 219-226.

Landesman, S., & Butterfield, E. C. (1987). Normalization and deinstitutionalization of

mentally retarded individuals: Controversy and facts. *American Psychologist, 42,* 809-816.

Larson, S., & Lakin, K. (1991). Parent attitudes about residential placement before and after deinstitutionalization: A research synthesis. *Journal of the Association for Persons with Severe Handicaps, 16,* 25–38.

Lemay, R. A. (2009). Deinstitutionalization of people with developmental disabilities: A review of the literature. *Canadian Journal of Community Mental Health, 28,* 181-194.

Lynch, P., Kellow, J., & Wilson, V. (1997). The impact of deinstitutionalization on the adaptive behaviour of adults with mental retardation. *Education and Training in Mental Retardation and Developmental Disabilities, 32,* 255-261.

Martin, L. (2004). *Assessing the needs of adults with intellectual disability in different care settings: Development and evaluation of the interRAI-intellectual disability (interRAI-ID).* Waterloo, ON: University of Waterloo.

Martin, L., Hirdes, J. P., Fries, B. E., & Smith, T. F. (2007). Development and psychometric properties of an assessment for persons with intellectual disability-the interRAI ID. *Journal of Policy and Practice in Intellectual Disabilities, 4,* 23-29.

Molony, H., & Taplin, J. (1988). Deinstitutionalisation of people with developmental disability. *Australia and New Zealand Journal of Developmental Disabilities, 14,* 109-122.

Molony, H., & Taplin, J. (1990). The deinstitutionalization of people with developmental

disability under the Richmond Program: I. Changes in adaptive behaviour. *Australia and New Zealand Journal of Developmental Disabilities, 16,* 149-159.

Naumes, W., Naumes, M. J. (2006). The art and craft of case writing (2nd ed.). Armonk, NY: M.E. Sharp.

Nirje, B. (1999). Formulating the Normalization principle. In Flynn, R. J. and Lemay, R. A. (ed.), *A quarter-century of Normalization and Social Role Valorization: Evolution and impact.* Ottawa, Canada: University of Ottawa Press.

Nottestad, J.A., & Linaker, O.M. (2002). Predictors for attacks on people after deinstitutionalization. *Journal of Intellectual Disability Research, 46,* 493-502.

Nottestad, J.A., Stromgren, B., & Linaker, O.M. (2000). Psychiatric and behavioural disturbances in elderly mentally retarded before and after deinstitutionalization. *Nordic Journal of Psychiatry, 54,* 281-286.

O'Neill, J., Brown, M., Gordon, W., Orazem, J., Hoffman, C., & Schonhorn, R. (1990). Medicaid versus state funding of community residences: Impact on daily life of people with mental retardation. *Mental Retardation, 28,* 183-188.

Parish, S. L. (2005). Deinstitutionalization in two states: The impact of advocacy, policy, and other social forces on services for people with developmental disabilities. *Research & Practice for Persons with Severe Disabilities, 30,* 219-231.

Perry, J., & Felce, D. (1995). Objective assessments of quality-of-life How much do they agree with each other. Journal of Community & Applied Social Psychology, 5, 1-19.

Perry, J., & Felce, D. (2005). Factors associated with outcome in community group homes. *American Journal on Mental Retardation, 110,* 121-135.

Radford, J. P., & Park, D.C. (1999). Historical overview of developmental disabilities in Ontario. In I. Brown & M. Percy (Eds.) *Developmental Disabilities in Ontario* (pp.1-16). Toronto: Front Porch.

Raphael, D., Brown, R., & Renwick, I. (1999). Psychometric Properties of the Full and Short Versions of the Quality of Life Instrument Package: results from the Ontario province-wide study. *International Journal of Disability, Development and Education, 46,* 157-168.

Robertson, J., Emerson, E., Hatton, C., Elliott, J., McIntosh, B., Swift, P., Krinjen-Kemp, E., Towers, C., Romeo, R., Knapp, M., Sanderson, H., Routledge, M., Oakes, P., & Joyce, T. (2007a). Person-centred planning: factors associated with successful outcomes for people with intellectual disabilities. *Journal of Intellectual Disability Research, 51,* 232-243.

Robertson, J., Hatton, C., Emerson, E., Elliott, J., McIntosh, B., Swift, P., Krinjen-Kemp, E., Towers, C., Romeo, R., Knapp, M., Sanderson, H., Routledge, M., Oakes, P. & Joyce. T. (2007b). Reported barriers to the implementation of person-centred planning for people with intellectual disabilities in the UK.

Rojahn, J., Matson, J. L., Lott, D., Esbensen, A. J., Smalls, Y. (2001). The behavior problems inventory: an instrument for the assessment of self-Injury, stereotyped behavior, and aggression /destruction in individuals with developmental disabilities. *Journal of Autism and Developmental Disorders, 31,* 577-588.

Romaniuk, C. & Miltenberger, R. G. (2001). The influence of preference and choice of activity on problem behaviour. *Journal of Positive Behaviour Interventions, 3,* 152-159.

Romaniuk, C., Miltenberger, R., Conyers, C., Jenner, N., Jurgens, M., & Ringenberg, C. (2002). The influence of activity choice on problem behaviours maintained by escape versus attention. *Journal of Applied Behaviour Analysis, 35,* 349-362.

Rudkin, A. & Rowe, D. (1999). A systematic review of the evidence base for lifestyle planning in adults with learning disabilities: implications for other disabled populations. *Clinical Rehabilitation, 13,* 363-372.

Scheerenburger, R.C. (1983). *A history of mental retardation.* Baltimore: Paul H. Brookes.

Shogren, K. A., Faggella-Luby, M. N., Bae, S. J. & Wehmeyer, M. L. (2004). The effect of choice-making as an intervention for problem behavior: A meta-analysis. *Journal of Positive Behaviour Interventions, 6,* 228-237.

Smith, D. (1981). *Obstacles: Report of the special committee on the disabled and the handicapped.* Ottawa: Ministry of Supply and Services Canada.

Stancliffe, R.J., & Abery, B.H. (1997). Longitudinal study of deinstitutionalization and exercise of choice. *Mental Retardation, 35,* 159-169.

Stancliffe, R.J., Hayden, M.F., Larson, S.A., & Larkin, K.C. (2002). Longitudinal study on the adaptive and challenging behaviours of deinstitutionalized adults with mental retardation. *American Journal on Mental Retardation, 107,* 302-320.

Strauss, D. & Kastner, T. A. (1996). Comparative mortality of people with developmental disabilities in institutions and community. *American Journal on Mental Retardation, 101,* 26-40.

Taylor, S. J. (2001). The continuum and current controversies in the USA. *Journal of Intellectual & Developmental Disability, 26,* 15-33.

Trent, J. W. (1994). *Inventing the Feeble Mind: A History of Mental Retardation in the United States.* Berkley: University of California Press.

Tyrer, F. & McGrother, C. (2009). Cause-specific mortality and death certificate reporting in adults with moderate to profound intellectual disability. *Journal of Intellectual Disability Research, 53,* 898-904.

Widrick, G.C., Bramley, J.A., & Frawley, P.J. (1997). Psychopathology in adults with mental retardation before and after deinstitutionalization. *Journal of Developmental and Physical Disabilities, 9*, 223-242.

Yin, R. K. (2003). Case study research: Design and methods (3rd ed.). Thousand Oaks, CA: Sage Publications.

Young, L., & Ashman, A.F. (2004a). Deinstitutionalization in Australia part I: Historical perspective. *The British Journal of Developmental Disabilities, 50,* 21-28.

Young, L., & Ashman, A.F. (2004b). Deinstitutionalization for older adults with severe mental retardation: Results from Australia. *American Journal on Mental Retardation, 109,* 397-412.

Table 1

Pre and Post InterRAI-ID Data for Degree of Family Involvement

	Peter	Angie	Jane
	Q2. Strong and supportive relationship with family?		
Pre	Yes	Yes	No
Post	Yes	Yes	Yes
	Q3b. Visit with a long-standing social relation or family?		
Pre	8-30 days ago	Never	Never
Post	More than 30 days ago	More than 30 days ago	More than 30 days ago
	Q3c. Other interaction with long-standing social relation or family member—*e.g., telephone or e-mail?*		
Pre	More than 30 days ago	Never	Never
Post	Never	More than 30 days ago	More than 30 days ago
	Q4d. Overnight stay of 1 or more nights at home of family member or long-standing social relation?		
Pre	Unable to determine	Never	Never
Post	Never	Never	Never
	Q5a. Conflict with or repeated criticism of family or friends?		
Pre	No	No	No
Post	No	No	No
	Q5c. Family/close friends are persistently hostile toward person?		
Pre	No	No	No
Post	No	No	No

Table 2

Post Data from Quality of Life Questionnaire

	Peter	Angie	Jane
Degree of family involvement			
How important to him/her is being close to some people in his/her family?	2	4	5
How happy is he/she with his/her closeness to some people in his/her family?	5	3	1
To what extent does he/she make his/her own decisions about spending time with family and friends?	1	1	1
To what extent are there opportunities for him/her to spend time with family and friends?	3	5	5
Participation in Community Leisure Activities and Interactions with Community Members			
How important to him/her is going to places in the community (store, restaurant, etc.)?	5	5	5
How happy is he/she with the places he/she goes to in the community (store, restaurant)?	5	5	5
To what extent does he/she make his own decisions about the places he/she goes in the community (store, restaurant)?	5	5	5
To what extent are there opportunities for him/her to go to more or different places in the community?	5	5	5
How important to him/her is visiting and socializing with others?	3	5	1
How happy is he with his/her visiting and socializing?	4	5	1

To what extent does he make his own decisions about his/her visiting and socializing?	5	1	5
To what extent are there opportunities for him to visit and socialize more or in different ways?	3	5	5
Opportunities for Choice Making			
To what extent does he/she make his own decisions about looking after his/her physical health?	2	1	1
To what extent does he/she make his/her own decisions about the food he/she eats?	4	2	1
To what extent does he/she make his/her own decisions about his/her hygiene and body care?	2	1	1
To what extent does he/she make his own decisions about where he/she lives?	1	1	1
To what extent does he make his own decisions about his/her space for privacy?	5	1	1
To what extent does he make his own decisions about what neighborhood he lives in?	1	1	1
To what extent does he/she make his/her own decisions about having/not having a spouse or special person?	2	1	1
To what extent does he/she make his/her own decisions about spending time with family and friends?	1	1	1
To what extent does he/she make his/her own decisions about who his friends are?	3	1	1
To what extent does he/she make his own decisions about taking courses or training in his/her community?	1	1	1

To what extent does he/she make his/her own decisions about having/not having 1meaningful work in the community?	1	1	1
To what extent does he/she make his/her own decisions about the places he/she goes in the community (store, restaurant)?	5	5	5
To what extent does he/she make his/her own decisions about what he/she does during the day?	4	3	5
To what extent does he/she make his/her own decisions about what household work he/she does?	4	1	5
To what extent does he/she make his/her own decisions about looking after/not looking after other people or pets?	4	1	1
To what extent does he/she make his/her own decisions about his/her visiting and socializing?	5	1	5
To what extent does he make his own decisions about his hobbies?	5	4	5
To what extent does he/she make his/her own decisions about his/her casual leisure activities (TV, reading, walks, etc.)?	5	4	5
To what extent does he/she make his/her own decisions about learning new things?	4	4	4
To what extent does he/she make his/her own decisions about solving his/her problems?	1	1	4
To what extent does he/she make his/her own decisions about the things that change in his/her life?	4	1	5

Note: Rating Scale: 1=not at all, 2=a little, 3= some, 4=quite a bit, 5= a lot

Table 3

Pre and Post InterRAI-ID Data for Community Involvement

	Peter	Angie	Jane
	Q4. Activity preferences and involvement.		
Pre	Q4f. Dancing? Preferred, regularly involved but not in the last 3 days Q4o. Walking outdoors? Preferred, regularly involved but not in the last 3 days	Q4m. Spiritual or religious activities? Preferred, involved in the last 3 days. Q4n. Trips or shopping? Preferred, regularly involved but not in last 3 days Q4o. Walking outdoors? Preferred, regularly involved but not in last 3 days	Q4m. Spiritual or religious activities? Preferred, not involved
Post	Q4n.Trips or shopping? Preferred, involved in the last 3 days Q4o.Walking outdoors? Preferred, involved in the last 3 days	Q4f. Dancing? Preferred, regularly involved but not in last 3 days Q4m. Spiritual or religious activities? Preferred, involved in the last 3 days Q4n. Trips or shopping? Preferred, involved in the last 3 days. Q4o. Walking outdoors? Preferred, involved in the last 3 days	Q4f. Dancing? Preferred, not involved Q4m. Spiritual or religious activities? Preferred, regularly involved but not in last 3 days Q4n. Trips or shopping? Preferred, involved in the last 3 days Q4o. Walking outdoors? Preferred, regularly involved but not in

			last 3 days
	Q5a: At ease interacting with others?		
Pre	Exhibited on 1-2 of last 3 days	Exhibited daily in last 3 days	Exhibited daily in last 3 days
Post	Exhibited daily in last 3 days	Exhibited daily in last 3 days	Exhibited on 1-2 of last 3 days
	Q5b: At ease doing planned or structured activities?		
Pre	Exhibited daily in last 3 days	Exhibited daily in last 3 days	Exhibited daily in last 3 days
Post	Exhibited daily in last 3 days	Exhibited daily in last 3 days	Exhibited on 1-2 of last 3 days
	Q5c: Pursues involvement in activities of residential setting or community—*e.g., makes or keeps friends, involved in group activities, responds positively to new activities, assists at religious services.*		
Pre	Not present	Not present	Not present
Post	Exhibited daily in last 3 days	Present but not exhibited in last 3 days	Not Present
	Person prefers change (when asked) Q6b: Recreational activities—*e.g., type, number, or level of participation?*		
Pre	Could not (would not) respond	Could not (would not) respond	No
Post	Could not (would not) respond	Could not (would not) respond	Could not (would not) respond
	Q3a: Participation in social activities of long-standing interest?		
Pre	Never	Never	8-30 days ago
Post	In last 3 days	In last 3 days	In last 3 days

Table 4

Pre and Post InterRAI-ID Data for Opportunities for Choice Making

	Peter	Angie	Jane
	Person prefers change (when asked) Q6a. Paid employment—*e.g., type, hours, pay*?		
Pre	Could not (would not) respond	Could not (would not) respond	No
Post	Could not (would not) respond	Could not (would not) respond	Could not (would not) respond
	Person prefers change (when asked) Q6b: Recreational activities?		
Pre	Could not (would not) respond	Could not (would not) respond	No
Post	Could not (would not) respond	Could not (would not) respond	Could not (would not) respond
	Person prefers change (when asked) Q6c: Living arrangements—*e.g., location, type, who lives with*?		
Pre	Could not (would not) respond	Could not (would not) respond	No
Post	Could not (would not) respond	Could not (would not) respond	Could not (would not) respond
	Person prefers change (when asked) Q6d: Daily routine—*e.g., diet, sleep schedule, clothes to wear*?		
Pre	Could not (would not) respond	Could not (would not) respond	No
Post	Could not (would not) respond	Could not (would not) respond	Could not (would not) respond
	Q2: Cognitive skills for daily decision-making?		
Pre	Severely impaired—*Never or rarely makes decisions*	Severely impaired—*Never or rarely makes decisions*	Severely impaired—*Never or rarely makes decisions*
Post	Minimally impaired—*In*	Severely impaired—*Never or rarely*	Moderately impaired—*decisions*

	recurring situations, decisions become poor or unsafe; cues/supervision necessary at those times.	*makes decisions*	*consistently poor or unsafe; cues/supervision required at all times.*
Q3: Change in decision-making as compared to 90 days ago?			
Pre	No change	No change	No change
Post	No Change	No change	No change

Table 5

Post Data from Assessor Questionnaire

	Peter	Angie	Jane
Is this person accepted by others in his immediate neighborhood (outside immediate living environment)?	Yes	Yes	Yes
Does this person interact in a meaningful way with people within the larger community?	Somewhat	Somewhat	No
Does this person have access to community-based education and employment opportunities?	Somewhat	No	No
Does this person have access to community-based social and medical services?	Yes	Yes	Yes
Does this person have access to community buildings and services such as worship centers, libraries, shopping malls, restaurants, and recreational facilities?	Yes	Yes	Yes

Appendix A

CASE STUDY RECORD FORMS: HISTORY QUESTIONNAIRE DERIVED FROM ARCHIVES AND INTERVIEWS…

STEP 1: INTERVIEWING THE INDIVIDUAL AND SIGNIFICANT CAREGIVERS AND REIVEWING ALL DOCUMENTATION.

(Develop from review of the files including all past evaluations/ programs and fill in blanks with observations and staff interviews)

1. **Where has this person lived previously? Why were moves precipitated?**

2. **Create a timeline of the person's behavioral/psychiatric history and significant life events (Provide dates to show correlations).**

Behavioral/Psychiatric History

/_____/_____/_____/_____/_____

Significant Life Events

/_____/_____/_____/_____/_____

STEP II: BIOMEDICAL/ PSYCHIATRIC ASPECTS

1. **Does the individual have any of the following:**
   ( ) known syndromes
   ( ) medical conditions
   ( ) ongoing medical problems
   ( ) psychiatric diagnoses

   Specify any and all of the above:

2. **What is the health status of the person and has the health of the individual changed recently? How? When?**

3. **Has the person been hospitalized within the past 5 years and if so for what reason?**

4. **Does the person experience problems in any of the following:**
   ( ) activity level or energy_____
   ( ) socialization_____
   ( ) interest in previous activities_____
   ( ) eating_____ Note any special dietary needs_____

   ( ) skills_____
   ( ) bowel or bladder _____
   ( ) irritability_____
   ( )sleep_____ Describe

   If so, please describe when did the problem start and how?

5. **Does the behavior:**
   ( ) come out of the blue
   ( ) show no predictable pattern
   ( ) occur with hallucinations or delusions
   ( ) occur with repetitive verbal behavior
   ( ) occur with specific repetitive physical behavior

If so, please describe:

6. List present medications/ dosages and reason for prescription? Have medications for the individual changed recently? How and when?

7. Could the medications in any way contribute in isolation or in combination to the any problems the person may be experiencing? If so how?

8. Develop a timeline of the medical/ medication history to the behavioral/psychiatric changes (provide dates to show correlations)

Medical History/Medication Changes

/_____/_____/_____/_____/____

Behavioral/Psychiatric Changes

/_____/_____/_____/_____/____

9. What medical/psychiatric considerations must be taken into account when the person is transferred? (support/ specialists/ personal vulnerabilities/ setting events/ staff training etc.)

STEP III: PSYCHOLOGICAL ASPECTS

1. **Describe the strengths that this individual presents and how they contribute to the person's ability to adapt and enjoy life?**

2. **a) How does the person communicate?**
( ) words, ( ) sentences, ( ) sign language, ( ) picture boards. ( ) blissymbols. ( ) gestures, ( ) behaviors

Describe:

b) Does the person have:

i. ( ) an accessible means to communicate (picture board)
ii. ( )communication that results in desired attention from others
iii. ( ) communication that results in desired outcomes
iv. ( ) other

c) Does the person make his/her physical needs known? How?

d) Does the person make feelings known? How?

e) Does the person communicate preferences and choices? How?

f) Can the person indicate need for help? How?

g) Does *the person express needs behaviourally? How?*

3. Does the individual experience difficulty in dealing with some situations, how is it manifested?

4. What skills does the person use to relax/calm?

5. **What coping mechanisms help him/ her to cope?**

6. **Have there been habilitative programmes in place for the individual to increase independence, adaptation or as replacement for challenging behaviours? If so what are they, were they effective and are they still advised?**

7. **What habilitative elements should be present in the new setting? (i.e. teaching communication or coping skills etc.)**

STEP IV: SOCIOCULUTRAL FACTORS

1.

   a) **Are there situations where the individual experiences more or less satisfaction/ dissatisfaction in the day?**

   b) **Are there times of the day when the person experiences more or less satisfaction/ dissatisfaction?**

2. **Are any of these situations associated with dissatisfaction for the person:**
   - ***( ) if there is excessive stimulation***
   - ***( ) following requests or directives***
   - ***( ) following a demand to do a task***
   - ***( ) when doing difficult/challenging tasks***
   - ***( ) when it is noisy***
   - ***( ) when there is excessive activity***
   - ***( ) when it is crowded***
   - ***( ) when teased/provoked by others***
   - ***( ) in the presence of specific people***
   - ***( ) in specific settings/activities***
   - ***( ) at specific times of the day***
   - ***( ) when situations are unfamiliar***
   - ***( ) when situations are frightening***
   - ***( ) when changing to a less desired activity***
   - ***( ) when in a prolonging activity***
   - ***( ) at low activity time***
   - ***( ) at low reinforcement time***
   - ***( ) when reinforcement is diverted elsewhere***

( ) when others are reinforced for their behavior
( ) when a preferred/desired activity is ending
( ) in presence of preferred people
( ) if communication is ignored or request denied
( ) if stopped/interrupted from a desired activity
( ) if praised

Describe in more detail those situations that apply.

3. What interactional / environmental changes might create a situation more suited to the needs of the individual?

( ) reducing/altering approach to or number demands
( ) changing activities or timing of activities
( ) providing choice of activities
( ) leave alone
( ) increased time for personal comfort needs
( ) changes in meals, toileting, rest routines
( ) reduce demands at vulnerable times
( ) letting the person do anything desired
( ) providing choices of activities
( ) increased personal support time
( ) increased access to reinforcers
( ) greater access to desired activities & materials throughout the day
( ) increased opportunity to engage in stimulating activities
( ) increased/partial participation in more activates
( ) more access to materials
( ) more access to leisure activities or hobbies
( ) other

Describe in more detail:

4. How does the person react:

( ) when hungry, thirsty, tired, ill
( ) before or during menses
( ) when afraid, tense or anxious
( ) just before or after seizures

For each item checked, describe in detail:
When hungry, she can verbally indicate the need to eat

5. **Does the person appear more satisfied:**
   ( ) when alone
   ( ) independent of who is present
   ( ) in routine/familiar/less active situations
   ( ) when in unchallenging situations

   To those checked above, describe each:

6. **Does the person participate in the community? What activities are valued by the individual? What activities present challenges? Are there specific community social situations that are problematic? How are safety issues assured when in the community?**

7. **Does the person have known hobbies/ interests/ sporting activities? If you allowed this individual to do whatever he/she wanted what would it be?**

8. **Does the person show spiritual needs (participation in religious activities/ observation of special days or holidays)? How are these best met?**

STEP V. BEHAVIOURAL CONCERNS

1. **What are the behavioural concerns if any? If none proceed to step VI.**

2. **Why is it seen as a problem?**
   - *a. ( ) occurs too frequently (how frequent?)*_____
   - *b. ( ) occurs for long periods of time (duration?)*_____
   - *c. ( ) is very intense (specify)*_____
   - *d. ( ) is not appropriate to place, time, people etc. (specify)*_____
   - *e. ( ) causes damage/health risk to individual or others (specify)*_____
   - *f. ( ) causes damage to property (specify)*_____
   - *g. ( ) interferes with the individual's opportunity to socialize, learn or be involved in*
     - *i. Desired activities (specify)*_____
   - **h.** *( ) is disruptive to others (specify)*_____

3. **Expand on any of the above:**

4. **Does the behavior:**
   - *a. ( ) occur in isolation*
   - *b. ( ) cluster with other behaviors*
   - *c. ( ) have early signs that signal you it is going occur*
   - *d. ( ) occur constantly or does it change over time (i.e. cycle)*
   - *e. ( ) appear to have changed recently*

5. **Describe any of the above you checked:**

6. **Has this behavior recently changed and if so how?**

7. **Have there been other changes apparent in the individual at this time? (i.e., physical appearance, interests, sleep, appetite, energy, responses to people or the environment)?**

8. **What possible functions does the behavior serve:**

Does the behavior serve to:	Specific functions	Possible Hypotheses
allow the individual to avoid/escape/ remove or delay an undesired	*( ) attention, interactions* *( ) activity or task* *( ) demands* *( ) setting events (i.e., noise/lights/crowds)* *( ) other*	*Negative Reinforcement*
Gain desired	*( )attention, counselling, physical intervention, reprimands, individual time* *( ) tangible outcomes (i.e., food/object)* *( ) change in activity* *( ) continence of an activity*	*Positive Reinforcement*
Provide	*( ) interruptions to discomfort* *( ) relief from discomfort* *( ) physical needs*	*Negative Reinforcement*
Provide	*( ) sensory stimulation*	*Positive Reinforcement*
Communicate	*( ) a desire to escape and avoid a situation/ person/event* *( ) pain, anxiety, fear, hunger, or discomfort* *( ) desire for attention, change of activity, change in reinforcement* *( ) no intention to communicate*	*Negative Reinforcement* *Negative Reinforcement* *Positive Reinforcement*

9.

a) Currently what reaction does the behavior appear to most often receive? Describe:

b) Does the behavior result in gaining the person:

i. ( ) accelerated attention

ii. ( ) physical contact
iii. ( ) gaining access to desired possessions
iv. ( ) change of activity or access to an activity
v. ( ) individual supervision
vi. ( ) counselling by staff'
vii. ( ) access to preferred people
viii. ( ) help or comfort
ix. ( ) a tangible item
x. ( ) is scolded or reprimanded
xi. *( ) intervene to interrupt the behavior*

c) Does the behavior result in changing/reducing some situations such as:

i. ( ) activity is discontinued
ii. ( ) interaction is stopped
iii. ( ) person is removed from situation or time out
iv. ( ) others removed from situation
v. ( ) activity is delayed
vi. ( ) demands are reduced
vii. ( ) noise is reduced

d) Was the response to the behavior consistent across time and people? If not describe.

e) Did the observations support the hypotheses regarding the interviews with caregivers? If so what is the motivation(s) for the behavior(s)?

STEP VI. COMPARISON OF HISTORY AND INTERVIEW DATA WITH ESSENTIAL PLAN

	Elements that should be considered in Transitional Planning to ensure positive quality of life	Elements that are in the Essential Plan	Discrepancy	Comments
Medical/ Psychiatric				

(including health/ mobility/ fitness/ nutrition)				
Socio-Environmental a) Social (meaningful relationships) b) Physical "at home in environment"/ safety/ privacy) c) Programmatic (purposeful meaningful daily activities) d) Leisure (activitiies/ hobbies) d) Spirtual (values/ celebrations) e) Community Inclusion				
Psychological (initiating positive behaviour/ sense of self/coping skills/ personal expression and choices and opportunity for learning and change)				
Behavioural (minimization of distress)				

***Further* considerations for placement observations:**

Appendix B

INTERVIEW QUESTIONS: FRONT LINE STAFF (Community)

Case Number:
Date:
Period of Interview: Post

A. Adjustment/adaptation to the transition

1. How well is the individual adapting to the new situation?

2. Would you say the person has accepted the transition?

3. If so how long did it take for the transition to be accepted?

4. Has the person developed strong relationships with staff? Can you give me some examples?

5. Has the person developed strong relationships with peers? Can you give me some examples?

B. Setting and Supports

6. How appropriate do you feel this setting is for the individual? Why?

7. What is the current ratio of staff to this individual during the day (:); at night (:), in the community (:)? %

8. Do you think the staffing is sufficient to meet the person's needs?

9. What type of training has the staff received in the past few months to support the needs of this individual? Is it sufficient and appropriate? Is there need for more training?

10. Does the person see a professional (name professional), and if so how often? If these re-new or if there are changes in professional support why were services added or deleted?

Physician	
Dentist	
Behavior Therapist	
Psychiatrist	
Physiotherapist	
Occupational Therapist	
Speech/ Communication	
Social Worker	
Neurologist	
Psychologist	
Other	

11. Are there services that are needed but not available?

12. Would you say the support services are sufficient and appropriate for the person?

C. Daily Routines

13. What time of day does the person awake on weekdays___ weekends____Does the person awoken or does he/she awake themselves?

14. What time is breakfast on weekdays_____weekends_____? What time is lunch on weekdays _____ weekends ?. What time is dinner on weekdays_____ weekends ?

15. Does the person help in meal preparation? How?

16. How is his/her appetite? Are there any challenges at mealtime?

17. What time is bedtime on weekdays_____ weekends_____? Who initiates bedtime?

18. When does the person bathe? Daily, every other day, weekly. Is bath at a scheduled time or initiated by the individual?

19. How is the person's sleeping patterns? Does he/she awake during the night or is woken by staff? Why?

D. Activities and Community Inclusion

20. Are you pleased with the amount and appropriateness of meaningful/personally fulfilling things the person has to do each day?

21. Are these new interests?

22. Does the individual exercise daily?

23. What daily household activities does the person participate?

24. Does the person have a day programme? Where is it? Is it individualized or participation in a group activity? Do you think it is a good match for the individual?

25. Has the person shown increase in independence since moving to your agency or since our last visit? Can you give examples?

26. I will name some activities and ask you to say if the person does these things frequently (monthly), sometimes (less than once a month) or never.

	Frequently (at least once a month)	Sometimes or rarely (less than once a month)	Never
Dining in a restaurant			
Receiving visits from friends			
Receiving visits from relatives			
Visiting friends (outside the home)			
Visiting relatives			
Telephone calls to or from family			
Telephone calls to or from friends			
Socialization with peers			
Going to place of worship			
Going to a movie			
Going shopping			
Going on a holiday			
Attending a concert or play			
Watching a sporting event			
Visiting a social club			
Visiting a park or going for a walk			
Going to a barber/hairdresser			
Are there other activities the person does that I have not mentioned?			

27. How is the person actively <u>included</u> in the community? What leisure and community activities does the person regularly participate?

28. Has the individual had contacts with neighborhood or general community? Have these contacts been positive or negative?

29. Has family and friend contact has changed since the move or last evaluation?

30. Since placement or our last evaluation have family or friends helped the individual relative to advocacy, support/advice, or emotional support?

31. Has the individual's new setting affected the relationships with family and friends in the past few months? Can you give some examples?

32. Has the individual gone with family or friends on an overnight stay since the transition or last evaluation?

33. Has the individual shared meals with family or friends since the transition?

E. Changes since Transition

34. What choices about his/her own day has the person been making? Is it increasing?

35. Has the person experienced a change in medical status/ health? Please explain. Has there been hospitalization since transition or last evaluation? Have there been medication changes or diagnostic changes?

36. Has the person experienced behavioral challenges since transition or since last evaluation? Are the challenges greater or less than expected from the Essential Elements Plan or previous period?

37. How are they being managed? Are the strategies working?

38. Has the individual required police contact? If so please elaborate.

39. What are the biggest changes in the individual since transition/ last evaluation?
    a. Health or mental health
    b. Interests
    c. Adaptive skills
    d. Self-care
    e. Communication
    f. Social Skills
    g. Other… please give examples

F. Quality of Life

40. Tell me about the individual's quality of life today.
What do you think is the most important factors responsibility for the quality of life? Would you recommend things to improve his or her quality of life? Are there problems in accessing additional resources and if so why?

41. What new plans and goals do you have for this person today that you did not have previously?

42. Is there anything else you want to add to help us understand the person?

Summary

43. At this time if you would have changed anything for this person what would it have been? What are the lessons you wish to send forward to others?

Appendix C

INTERVIEW QUESTIONS: Family

Case Number:

Date:

Period of Interview: Post

1. How are you feeling about the placement at this time?

2. Has your family member adapted well to the new physical environment?

3. Has your family member adapted well to living in a smaller setting?

4. How are his/her relationships with the staff? With others living in the home?

5. Would you say the location is a good fit for your family member?

6. Are you satisfied that the design of the home is appropriate for your family member?

7. Are you satisfied with the staffing arrangements?

8. Does your family member have the level of professional/ medical supports recommended?

9. Are you pleased with the quality and access to needed professional/ medical supports?
10. Is there good communication with the new agency?

11. Are you geographically closer to your family member?

12. How often are you able to visit? Call? Have your family member visit?

13. What word describes the quality of life of your family member now?

14. Is anything happening that you did not anticipate?

Appendix D

INTERVIEW QUESTIONS: AGENCY ADMINISTRATIVE STAFF

Case Number:
Date:
Period of Interview: Post

1. How do you think this person is doing in the programme you designed? Tell me about it.

2. What supports are in place for the person currently? Are they sufficient? Are they accessible? Are their additional supports needed? Were some supports recommended but not needed. If so why?

3. How have the adaptations have you made to the setting to accommodate this person worked out?

4. Are you finding there were other adaptations that were needed or that some of the adaptations you made were unnecessary?

5. Do you feel the staffing is still sufficient? Do staff need additional training? Have they received any?

6. How has the individualized planning paid off or has it?

7. How has the family been involved? How often will you communicate with them?

8. How confident are you now that you will be able to successfully support this individual?

9. Does he or she pose any challenges that are unusual for your agency? If so what are these challenges? How do you plan to overcome them?

10. Do you feel the Essential Elements Plan still captures the needs of the person?

11. How does your current plan align with the Essential Elements Plan? Where if anywhere does it now differ?

12. At this time if you would have changed anything for this person what would it have been? What are the lessons you wish to send forward to others?

Appendix E

INTERVIEW QUESTIONS: FACILITY PLANNERS

Case Number:
Date:
Period of Interview: Post

1. Did you feel that the Essential Elements plan was ready for the person to move into the community? Are you confident that the implementation plan based on the Essential Elements Plan is in place?

2. What supports were arranged for when the person moved? Are there supports that should be in place but were not accessible? Why?

3. What adaptations have been made to the setting to accommodate this person? Has the agency been given supports to enable these adaptations to occur?

4. What specialized staff and training has been done? Are they being funded appropriately for this staffing ratio and training?

5. Has the planning been individualized? If so how?

6. How has the family been involved? How often will you communicate with them after the transfer?

7. How confident are you that the chosen agency will be able to successfully support this individual?

8. Does he or she pose any challenges that are unusual for this agency? If so what are these challenges? How do you see the agency overcoming them?

9. Do you feel the Essential Elements Plan captures the needs of the person?

10. How does the transitional plan align with the Essential Elements Plan? How will it be actualized? Where if anywhere will it differ?

11. How do you think this person is doing in the community programme that has been designed? Please tell me about it.

12. What supports are in place for the person currently? Are they sufficient? Are they accessible? Are their additional supports needed? Were some supports recommended but not needed. If so why?

13. How have the adaptations to the setting to accommodate this person worked out?

14. Are you finding there were other adaptations that were needed or that some of the adaptations you made were unnecessary?

15.Do you feel the staffing is still sufficient? Do staff need additional training? Have they received any?

16. How has the individualized planning paid off or has it?

17. How has the family been involved? How often will you communicate with them?

18. How confident are you now that you will be able to successfully support this individual?

19. Does he or she pose any challenges that are unusual for your agency? If so what are these challenges? How do you plan to overcome them?

20. Do you feel the Essential Elements Plan still captures the needs of the person?

21. How does your current plan align with the Essential Elements Plan? Where if anywhere does it now differ?

22. At this time if you would have changed anything for this person what would it have been? What are the lessons you wish to send forward to others?

Appendix F

OBSERVATION SHEET

Throughout the course of your visit with the individual maintain an active observation sheet of events that occur (observing approximately the 1st 10 minutes of each hour you spend). Observation times should be approximately 8 hours and include at least one mealtime.

Time	Setting and Activities	Observations/ Interactions

Appendix G

DISCREPENCY ANALYSIS BETWEEN OBSERVATIONS AND ESSENTIAL / TRANSITIONAL PLAN (post)

A. Is the type of setting group home ( ), apartment ( ), family home ( ) other ( )

_____

Consistent with that described in the Essential Elements Plan and Transitional Plan

If not why was a change recommended?

Describe the home in detail.

B. How many people with disabilities live with the person in his or her home (unit)?

_____

Describe the other people in the home and the interactions observed.

C. Does the person have a room of his or her own? Yes No Is this consistent with the Essential Elements Plan and if not why?

D. Describe the room. Is the room consistent with what was recommended in the Essential Elements and Transitional Plan and if not why?

E. What is the staffing and is it consistent with recommendations in the attached Essential Elements Plan? Yes No If not why?

F. From the records and interviews is the access to professional services as recommended in the Essential Elements Plan and if not why? Are they adequate and sufficient? What else is needed? Why are they not accessed?

Professional Services	**Currently receives**	**Frequency of Access**	**Were these in the Essential Plan?**	**Why were professional services added or deleted from the Plan?**
Physician				
Dentist				
Behaviour Therapist				
Psychiatrist				
Physiotherapist				
Occupational Therapist				
Speech/ Communication				
Social Worker				
Neurologist				
Psychologist				
Other				

G. Were these activities identified in the Essential Elements Plan? *Yes/ No*

H. Are there activities recommended in the Essential Elements Plan that are not available or accessible to the person? *Yes/ No*
If so why?

I. Were the above activities recommended in the Essential Elements Plan? Yes No

J. Have activities that were recommended in the Essential Elements Plan been accessed?
Yes No
a. If not why?

K. How relevant is the Essential Elements Plan to the person today*? Not relevant Somewhat relevant Very relevant*

Appendix H

Agency Staff Members Consent Form

Case Study: Facilities Initiative Review Evaluation

Lead Investigator and Contact Person for the Survey Study: Dr. Dorothy Griffiths

Principal Investigators Drs. Dorothy Griffiths and Rosemary Condillac
Co-Investigators Drs. Frances Owen, Jan Frijters
Centre for Applied Disability Surveys
Brock University
Tel: 905-688-5550

Research Coordinator

Introduction
The family of the individual noted in the accompanying letter has given permission for this individual to be included in the Facility Initiative Research Evaluation as a CASE STUDY.

Before you agree to participate in this research study, it is important that you read and understand the following explanation of the study. It describes the purpose, procedures, benefits, and risks associated with the study. All research is voluntary. You are free to withdraw at any time without penalty. If you have questions after you read through this form, ask someone in your agency. You should not sign this form until you are sure you understand everything on it.

Purpose of the Research
The purpose of the survey study is to contribute to an evaluation of the impact of the facility initiative in Ontario by gathering information from people who are living through this experience. We will be conducting 10 intensive case studies of individuals throughout the course of their first year in transition. The individual noted in the attached letter has been selected to participate in this study and the designated consent source (family member) for the person has consented to his or her participation. This study will provide an important look at the impact that community living plays in the lives of the persons who have been moved from the facilities.

Description of the Research
If you agree to participate in this study, you will be asked to be interviewed to complete several measures regarding the wellbeing and quality of life of the individual and to participate with our research assistants as they walk through the life of the individual. We will be asking you questions about the general wellbeing and functioning of the individual such as about the supports, health, activities and choices the person makes.

The Research Assistants will be occasionally taking video samples of a typical day in the life of the individual. This is being done to see the types of activities and interactions the person participates in on a daily basis. *These tapes will be analyzed and maintained in a confidential location in our laboratories. No video tape of you will be ever used except for the purpose described above without your expressed permission.*

The Research Assistants will visit the person and meet with you 4 times throughout their first year during the course of your working day. Each visit will take approximately 2 days. Although the full two days will not be spent solely with you or the individual, we ask that you be available for the full two days although only 1 day cumulatively will likely require your time. The Research Assistants will be interviewing other individuals and will be reviewing the individual's file and reports.

Potential Harms (Injury, Discomforts or Inconvenience):
If a question makes you feel uncomfortable, you can skip any question you don't want to answer. There is potential risk to you if the confidentiality of the information you give us were to be lost. To protect your confidentiality, your information will be kept on a coded form that does not have your name or other identifying information. We will keep your name and that of the resident and other identifying information (such as name and date of birth) on a separate form. All information you give us will be kept in a secure research office, and only authorized research staff will have access to the information. Nothing that you tell us will be shared with anyone from your agency, unless you disclose a situation of neglect or abuse in which case we are compelled to report this.

Potential Benefits:
There are no immediate benefits to you to participating in this study. You will not be paid for participating in this study. However each agency that participates and completes the requirements of the case study will receive an educational voucher. The voucher will be equal to a 50% discount on for four staff members of the organization to attend an educational event offered through the international dual diagnosis certificate programme (a $1500 value) summer 20010 or 11 or 15 free admissions to a training event offered by the centre for applied disability studies or a combination thereof. It is the agencies responsibility to decide how the voucher will be distributed.

Moreover the true benefits of this study will come from sharing what we learn from you and from other participants that may help others who are involved in facilities closures around the world.

Confidentiality and Privacy:
Confidentiality will be respected and no information that discloses your identity will be released or published without consent, unless required by law. For example, the researchers would have an obligation to report abuse should it be observed or reported during the course of our research.

All information that identifies you or the individual be kept confidential and stored and locked in a secure place that only study personnel will have access to. In addition,

electronic files that include identification information will be stored on a secure institutional network and will be password protected. It is important to understand that despite these protections being in place, experience in similar surveys indicates that there is the risk of unintentional release of information. The principal investigators will protect your records and keep all the information in your study file confidential to the greatest extent possible. The chance that this information will accidentally be given to someone else is small.

Publication of Results:
In the event that the results of this study are published or presented at conferences, seminars or other public forums, no individual information or identifying information will be released. We will give you a summary of the results of our study after it is over if you tell us you want one.
The results will be published both by the Ministry of Community and Social Services and the Investigators of this research and will be the subject of projects and theses for students in the Masters of Applied Disability Studies programme.

Reimbursement:
You will not be paid for participating in this study.

Participation and Withdrawal:
Participation in research is voluntary. If you choose not to participate, you will not be affected in any way. Your decision to participate or not participate in this research study will have no effect on you or your agency. If you would like to withdraw from the study, you can do so at any time by contacting us by phone.

Study Contact Information:
If you have any questions about this research study, you may contact Dr. Dorothy Griffiths (905-688-5550 ext 4069, e-mail dgirffiths@brocku.ca) or Dr. Rosemary Condillac (905-688-5550 ext. 5671, e-mail: rcondillac@brocku.ca) (collect calls accepted).

This study has been reviewed and approved by the Brock Research Ethics Board. (File #)
If you have questions or concerns about this study you may call the investigators listed above or the Brock University Research Ethics Officer in the Office of Research Services at 905-688-5550 ext. 3035, email: reb@brocku.ca.

For Agency staff members

Case Study: Facility Initiative Research Evaluation

Consent to Participate in a Research Study:

Consent:

I acknowledge that the research study described above has been explained to me and that any questions that I have asked have been answered to my satisfaction. I have been informed of my right to choose to not participate in the study. As well, the potential risks, harms and discomforts have been explained to me and I also understand the benefits of participating in the research study. I understand that I have not waived my legal rights nor released the investigators, sponsors, or involved institutions from their legal and professional duties. I know that I may ask now or in the future any questions I have about the study or the research procedures. I have been assured that records relating to me and the individual being surveyed will be kept confidential and that no information will be released or printed that would disclose my personal identity nor that of the individual being surveyed without permission unless required by law. I have been given sufficient time to read and understand the above information.

By signing this consent, I agree to participate in this study. I will be given a signed copy of this consent form.

X_____	_____	_____
Signature of Agency Staff Participant	Name (printed)	Date
X_____	_____	_____
Signature of Agency Staff Participant	Name (printed)	Date
X_____	_____	_____
Signature of Agency Staff Participant	Name (printed)	Date
X_____	_____	_____
Signature of Agency Staff Participant	Name (printed)	Date
_____	_____	_____
Signature of Investigator	Name (printed)	Date

Appendix I

Family Members Consent Form

Case Study: Facilities Initiative Review Evaluation

Lead Investigator and Contact Person for the Survey Study: Dr. Dorothy Griffiths

Principal Investigators Drs. Dorothy Griffiths and Rosemary Condillac
Co-Investigators Drs. Frances Owen, Jan Frijters
Centre for Applied Disability Surveys
Brock University
Tel: 905-688-5550

Research Coordinator

Introduction

Before you agree to participate in this research study, it is important that you read and understand the following explanation of the study. It describes the purpose, procedures, benefits, and risks associated with the study. All research is voluntary. You are free to withdraw at any time without penalty. If you have questions after you read through this form, ask someone in your agency. You should not sign this form until you are sure you understand everything on it.

Purpose of the Research

The purpose of the survey study is to contribute to an evaluation of the impact of the facility initiative in Ontario by gathering information from people who are living through this experience. We will be conducting 10 intensive case studies of individuals throughout the course of their first year following the transition, your family member has been selected as one of those case studies. This study will provide an important look at the individual stories of those individuals who are affected by the Facility Initiative and the perspectives of their families.

Description of the Research

If you agree to participate in this study, you will be asked to be interviewed four times throughout the year following placement then 3, 6 and 12 months following the first visit). The purpose of the interviews is to maintain an ongoing story from the perspective of the transition experience on your family member and you. You will be asked about the transitional process and how you feel your family member is doing and your satisfaction with the supports that are available. Each interview will take approximately ½ hr to 1 hr out of your time. The Research Assistants will also be interviewing other individuals,

visiting your family member and speaking with him/her, collecting data and reviewing the individual's file and reports.

Some of the people moving from the facility to the community are able to answer questions about their experiences. We would like to ask the following questions of your family member if the person can and agrees to speak with us. The questions we would ask prior to the move are: Do you know where you are moving to? Have you visited the new place yet? Did you like it? Tell me about it. Have you met the people who will help you there? Did you like them? What do you think it will it be like? Do you think this is a good place to be going? How do you feel about leaving_____? What will change in your new place?

Then at 3,6,and 12 months we would revisit and ask: . *Would you like to talk to me for a little while about how you feel about your new home?* Will you show me around your house? Show me the things you like about this new place? What do you like about living here? Who are they people you like to be with? What do you get to do in the day? Is this a good way to spend your day? Are there some things you don't like as much about this place?

Potential Harms (Injury, Discomforts or Inconvenience):
If a question makes you or your family member feel uncomfortable, we can skip any question that you or your family member do not want to answer. There is potential risk to you if the confidentiality of the information you give us were to be lost. To protect your confidentiality, your information will be kept on a coded form that does not have your name or other identifying information. We will keep your name and that of your family member and other identifying information (such as name and date of birth) on a separate form. All information you give us will be kept in a secure research office, and only authorized research staff will have access to the information.

Potential Benefits:
There are no immediate benefits to you to participating in this study. You will not be paid for participating in this study. Moreover the true benefits of this study will come from sharing what we learn from you and from other participants that may help others who are involved in facilities closures around the world.

Confidentiality and Privacy:
Confidentiality will be respected and no information that discloses your identity will be released or published without consent, unless required by law, such as in cases of suspected abuse or neglect. The Ministry nor the agencies involved will not have access to your comments or those of your family member.

All information that identifies you or the individual be kept confidential and stored and locked in a secure place that only study personnel will have access to. In addition, electronic files that include identification information will be stored on a secure institutional network and will be password protected. It is important to understand that

despite these protections being in place, experience in similar surveys indicates that there is the risk of unintentional release of information. The principal investigators will protect your records and keep all the information in your study file confidential to the greatest extent possible. The chance that this information will accidentally be given to someone else is small.

Publication of Results:
In the event that the results of this study are published or presented at conferences, seminars or other public forums, no individual information or identifying information will be released. We will give you a summary of the results of our study after it is over if you tell us you want one.
The results will be published both by the Ministry of Community and Social Services and the Investigators of this research and will be the subject of projects and theses for students studying in the Masters of Applied Disability Studies.

Reimbursement:
You will not be paid for participating in this study.

Participation and Withdrawal:
Participation in research is voluntary. If you choose not to participate, you will not be affected in any way. Your decision to participate or not participate in this research study will have no negative effect on you or your family member. If you would like to withdraw from the study, you can do so at any time by contacting us by phone.
Study Contact Information:
If you have any questions about this research study, you may contact Dr. Dorothy Griffiths (905-688-5550 ext 4069, e-mail dgirffiths@brocku.ca) or Dr. Rosemary Condillac (905-688-5550 ext. 5671, e-mail: rcondillac@brocku.ca) (collect calls accepted).

This study has been reviewed and approved by the Brock Research Ethics Board. (File #) If you have questions or concerns about this study you may call the investigators listed above or the Brock University Research Ethics Officer in the Office of Research Services at 905-688-5550 ext. 3035, email: reb@brocku.ca.

For Family Members

Case Study: Facility Initiative Research Evaluation

Consent to Participate in a Research Study:

Consent:
I acknowledge that the research study described above has been explained to me and that any questions that I have asked have been answered to my satisfaction. I have been informed of my right to choose to not participate in the study. As well, the potential risks, harms and discomforts have been explained to me and I also understand the benefits of participating in the research study. I understand that I have not waived my legal rights nor released the investigators, sponsors, or involved institutions from their legal and professional duties. I know that I may ask now or in the future any questions I have about the study or the research procedures. I have been assured that records relating to me and the individual being surveyed will be kept confidential and that no information will be released or printed that would disclose my personal identity nor that of the individual being surveyed without permission unless required by law. I have been given sufficient time to read and understand the above information.

By signing this consent, I agree to participate in this study and to have my family member as a participant in this study as discussed in the consent guidelines.

I will be given a signed copy of the consent form and guidelines.

X_____	_____	_____
Signature of Family	Name	Date
_____	_____	_____
Signature of Investigator	Name (printed)	Date

Appendix J

Agency Administrative Staff Consent Form

Case Study: Facilities Initiative Review Evaluation

Lead Investigator and Contact Person for the Survey Study: Dr. Dorothy Griffiths

Principal Investigators Drs. Dorothy Griffiths and Rosemary Condillac
Co-Investigators Drs. Frances Owen, Jan Frijters
Centre for Applied Disability Surveys
Brock University
Tel: 905-688-5550

Research Coordinator

Introduction
The family of the individual noted in the accompanying letter has given permission for this individual to be included in the Facility Initiative Research Evaluation as a CASE STUDY.

Before you agree to participate in this research study, it is important that you read and understand the following explanation of the study. It describes the purpose, procedures, benefits, and risks associated with the study. All research is voluntary. You are free to withdraw at any time without penalty. If you have questions after you read through this form, ask someone in your agency. You should not sign this form until you are sure you understand everything on it.

Purpose of the Research
The purpose of the survey study is to contribute to an evaluation of the impact of the facility initiative in Ontario by gathering information from people who are living through this experience. We will be conducting 10 intensive case studies of individuals throughout the course of their first year in transition. The individual noted in the attached letter has been selected to participate in this study and the designated consent source (family member) for the person has consented to his or her participation. This study will provide an important look at the impact that community living plays in the lives of the persons who have been moved from the facilities.

Description of the Research
If you agree to participate in this study, you will be asked to be interviewed four times throughout the year. The purpose of the interviews is to maintain an ongoing story from many perspectives of the transition experience of the individual you have accepted into your agency. The questions we will ask you relate to your perspective on the process, for example how has the transition worked for the individual, the challenges that have been

faced, the availability of appropriate supports, and how well the planning process prepared the agency to support the individual.

The Research Assistants will visit your agency 4 times throughout their first year. Each visit will take approximately 2 days however we will interview you for only ½ hr to 1 hr out of that time. The Research Assistants will be interviewing other individuals, including staff while on duty, observing the individual, conducting random video taping of the person engaged in an array of activities, collecting data and reviewing the individual's file and reports. The time with your staff members will take approximately 1 day each visit however some of this time will be spent in observations with the staff member as they conduct their day.

Potential Harms (Injury, Discomforts or Inconvenience):
If a question makes you feel uncomfortable, you can skip any question you don't want to answer. There is potential risk to you if the confidentiality of the information you give us were to be lost. To protect your confidentiality, your information will be kept on a coded form that does not have your name or other identifying information. We will keep your name and that of the resident and other identifying information (such as name and date of birth) on a separate form. All information you give us will be kept in a secure research office, and only authorized research staff will have access to the information.

Potential Benefits:
There are no immediate benefits to you to participating in this study. You will not be paid for participating in this study. However each agency that participates and completes the requirements of the case study will receive an educational voucher. The voucher will be equal to a 50% discount on for four staff members of the organization to attend an educational event offered through the international dual diagnosis certificate programme (a $1500 value) summer 20010 or 11 or 15 free admissions to a training event offered by the centre for applied disability studies or a combination thereof.

Moreover the true benefits of this study will come from sharing what we learn from you and from other participants that may help others who are involved in facilities closures around the world.

Confidentiality and Privacy:
Confidentiality will be respected and no information that discloses your identity will be released or published without consent, unless required by law, such as in cases of suspected neglect or abuse. No information that you share with us will used in any way except as collective data; the Ministry will not be privy to your comments.

All information that identifies you or the individual be kept confidential and stored and locked in a secure place that only study personnel will have access to. In addition, electronic files that include identification information will be stored on a secure institutional network and will be password protected. It is important to understand that despite these protections being in place, experience in similar surveys indicates that there is the risk of unintentional release of information. The principal investigators will protect

your records and keep all the information in your study file confidential to the greatest extent possible. The chance that this information will accidentally be given to someone else is small.

Publication of Results:
In the event that the results of this study are published or presented at conferences, seminars or other public forums, no individual information or identifying information will be released. We will give you a summary of the results of our study after it is over if you tell us you want one.
The results will be published both by the Ministry of Community and Social Services and the Investigators of this research and will be the topic projects or theses for students studying in the Masters of Applied Disability Studies.

Reimbursement:
You will not be paid for participating in this study.

Participation and Withdrawal:
Participation in research is voluntary. If you choose not to participate, you will not be affected in any way. Your decision to participate or not participate in this research study will have no effect on you or your agency. If you would like to withdraw from the study, you can do so at any time by contacting us by phone.

Study Contact Information:
If you have any questions about this research study, you may contact Dr. Dorothy Griffiths (905-688-5550 ext 4069, e-mail dgirffiths@brocku.ca) or Dr. Rosemary Condillac (905-688-5550 ext. 5671, e-mail: rcondillac@brocku.ca) (collect calls accepted).

This study has been reviewed and approved by the Brock Research Ethics Board. (File #) If you have questions or concerns about this study you may call the investigators listed above or the Brock University Research Ethics Officer in the Office of Research Services at 905-688-5550 ext. 3035, email: reb@brocku.ca.

For Agency Administrators

Case Study: Facility Initiative Research Evaluation

Consent to Participate in a Research Study:

Consent:
I acknowledge that the research study described above has been explained to me and that any questions that I have asked have been answered to my satisfaction. I have been informed of my right to choose to not participate in the study. As well, the potential risks, harms and discomforts have been explained to me and I also understand the benefits of participating in the research study. I understand that I have not waived my legal rights nor released the investigators, sponsors, or involved institutions from their legal and professional duties. I know that I may ask now or in the future any questions I have about the study or the research procedures. I have been assured that records relating to me and the individual being surveyed will be kept confidential and that no information will be released or printed that would disclose my personal identity nor that of the individual being surveyed without permission unless required by law. I have been given sufficient time to read and understand the above information.

By signing this consent, I agree to participate in this study. I will be given a signed copy of this consent form.

I however have some exceptions to this consent: The exceptions are:

X_____	_____	_____
Signature of Agency Administrator	Name (printed)	Date
_____	_____	_____
Signature of Investigator	Name (printed)	Date

Appendix K

Regional Facility Planners Consent Form

Case Study: Facilities Initiative Review Evaluation

Lead Investigator and Contact Person for the Survey Study: Dr. Dorothy Griffiths

Principal Investigators Drs. Dorothy Griffiths and Rosemary Condillac
Co-Investigators Drs. Frances Owen, Jan Frijters
Centre for Applied Disability Surveys
Brock University
Tel: 905-688-5550

Research Coordinator

Introduction
The family of the individual noted in the accompanying letter has given permission for this individual to be included in the Facility Initiative Research Evaluation as a CASE STUDY.

Before you agree to participate in this research study, it is important that you read and understand the following explanation of the study. It describes the purpose, procedures, benefits, and risks associated with the study. All research is voluntary. You are free to withdraw at any time without penalty. If you have questions after you read through this form, ask someone in your agency. You should not sign this form until you are sure you understand everything on it.

Purpose of the Research
The purpose of the survey study is to contribute to an evaluation of the impact of the facility initiative in Ontario by gathering information from people who are living through this experience. We will be conducting 10 intensive case studies of individuals throughout the course of their first year in transition. The individual noted in the attached letter has been selected to participate in this study and the designated consent source (family member) for the person has consented to his or her participation. This study will provide an important look at the impact that community living plays in the lives of the persons who have been moved from the facilities.

Description of the Research
If you agree to participate in this study, you will be asked to be interviewed three times throughout the year. The purpose of the interviews is to maintain an ongoing story from many perspectives of the transition experience of the individual you have helped place in

the community. Each interview will take approximately 1 hr out of your time. The questions we will ask are about the planning process for this individual and how well it has worked to create a smooth transition, Other questions might include the access to supports and challenges in the transitional process. The Research Assistants will be interviewing other individuals, observing the individual, collecting data and reviewing the individual's file and reports.
We will attempt to find a time during your work day that is convenient for our interview.

Potential Harms (Injury, Discomforts or Inconvenience):
If a question makes you feel uncomfortable, you can skip any question you don't want to answer. There is potential risk to you if the confidentiality of the information you give us were to be lost. To protect your confidentiality, your information will be kept on a coded form that does not have your name or other identifying information. We will keep your name and that of the resident and other identifying information (such as name and date of birth) on a separate form. All information you give us will be kept in a secure research office, and only authorized research staff will have access to the information.

Potential Benefits:
There are no immediate benefits to you to participating in this study. You will not be paid for participating in this study. Moreover the true benefits of this study will come from sharing what we learn from you and from other participants that may help others who are involved in facilities closures around the world.

Confidentiality and Privacy:
Confidentiality will be respected and no information that discloses your identity will be released or published without consent, unless required by law. No information you share with us will be shared with the staff or agencies involved or with the Ministry unless you inform us of neglect or abuse, which we are obligated to report to the authorities.

All information that identifies you or the individual be kept confidential and stored and locked in a secure place that only study personnel will have access to. In addition, electronic files that include identification information will be stored on a secure institutional network and will be password protected. It is important to understand that despite these protections being in place, experience in similar surveys indicates that there is the risk of unintentional release of information. The principal investigators will protect your records and keep all the information in your study file confidential to the greatest extent possible. The chance that this information will accidentally be given to someone else is small.

We will attempt to find a time during your work day that is convenient for our interview.

Potential Harms (Injury, Discomforts or Inconvenience):
If a question makes you feel uncomfortable, you can skip any question you don't want to answer. There is potential risk to you if the confidentiality of the information you give us were to be lost. To protect your confidentiality, your information will be kept on a coded

form that does not have your name or other identifying information. We will keep your name and that of the resident and other identifying information (such as name and date of birth) on a separate form. All information you give us will be kept in a secure research office, and only authorized research staff will have access to the information.

Potential Benefits:
There are no immediate benefits to you to participating in this study. You will not be paid for participating in this study. Moreover the true benefits of this study will come from sharing what we learn from you and from other participants that may help others who are involved in facilities closures around the world.

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Publication of Results:
In the event that the results of this study are published or presented at conferences, seminars or other public forums, no individual information or identifying information will be released. We will give you a summary of the results of our study after it is over if you tell us you want one.
The results will be published both by the Ministry of Community and Social Services and the Investigators of this research and will be the topic of projects or theses for students studying in the Applied Disability Programme.

Reimbursement:
You will not be paid for participating in this study.

Participation and Withdrawal:
Participation in research is voluntary. If you choose not to participate, you will not be affected in any way. Your decision to participate or not participate in this research study will have no effect on you or your agency. If you would like to withdraw from the study, you can do so at any time by contacting us by phone.

Study Contact Information:
If you have any questions about this research study, you may contact Dr. Dorothy Griffiths (905-688-5550 ext 4069, e-mail dgirffiths@brocku.ca) or Dr. Rosemary Condillac (905-688-5550 ext. 5671, e-mail: rcondillac@brocku.ca) (collect calls accepted).

This study has been reviewed and approved by the Brock Research Ethics Board. (File #) If you have questions or concerns about this study you may call the investigators listed above or the Brock University Research Ethics Officer in the Office of Research Services at 905-688-5550 ext. 3035, email: reb@brocku.ca.

For Regional Facility Planners

Case Study: Facility Initiative Research Evaluation

Consent to Participate in a Research Study:

Consent:
I acknowledge that the research study described above has been explained to me and that any questions that I have asked have been answered to my satisfaction. I have been informed of my right to choose to not participate in the study. As well, the potential risks, harms and discomforts have been explained to me and I also understand the benefits of participating in the research study. I understand that I have not waived my legal rights nor released the investigators, sponsors, or involved institutions from their legal and professional duties. I know that I may ask now or in the future any questions I have about the study or the research procedures. I have been assured that records relating to me and the individual being surveyed will be kept confidential and that no information will be released or printed that would disclose my personal identity nor that of the individual being surveyed without permission unless required by law. I have been given sufficient time to read and understand the above information.

By signing this consent, I agree to participate in this study. I will be given a signed copy of this consent form.

X_____	_____	_____
Signature of Regional Facility Planner	Name	Date
_____	_____	_____
Signature of Investigator	Name (printed)	Date